

the
Lowitja
Institute

Australia's National Institute for Aboriginal and
Torres Strait Islander Health Research

**Key Research Priorities for
Aboriginal and Torres Strait Islander People with a Disability**

Workshop Summary Report

23 October 2017

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Workshop agenda

Wednesday 4 October 2017

9.00am to 4.00pm

Suite 1, Level 2, 100 Drummond St, Carlton, Victoria

No.	Item.	Led by
9.00	Acknowledgement of Country	Leila Smith, Facilitator, the Lowitja Institute
9.15	Welcome and introduction	Romlie Mokak CEO, the Lowitja Institute
9.20	Disability research agenda in the Lowitja Institute	Kerry Arabena, Chairperson, Community Capability and the Social Determinants of Health Program Committee, The Lowitja Institute
9.30	Participants introduction	Leila Smith, Facilitator, the Lowitja Institute
9.40	Opening remarks from First People Disability Network CEO	Damian Griffis, CEO, First Peoples Disability Network
9.45	Current research trends in disability in the context of Aboriginal and Torres Strait Islander people	Scott Avery, Policy and Research Director, First People Disability Network
9.55	Opening remarks from the Disability Discrimination Commissioner	Alastair McEwin, Disability Discrimination Commissioner
10.00	Morning tea	
10.30	<u>Session 1:</u> Discussing barriers and enablers in the context of disability and its impact on Aboriginal and Torres Strait Islander people	Gregory Phillips, Facilitator, ABSTARR
11.30	<u>Session 2:</u> Priorities in the disability agenda- identify gaps in research and emerging themes/trends	Gregory Phillips, Facilitator, ABSTARR
12.30	Lunch	
1.00	<u>Session 3:</u> Developing key research questions	Gregory Phillips, Facilitator, ABSTARR
3.30	Summary	Romlie Mokak
4.00	Close	

Background

The Lowitja Institute hosted a one-day workshop on 4 October 2017 to discuss key research priorities for Aboriginal and Torres Strait Islander peoples with a disability. The workshop comprised of people with lived experience of disability, as well as, policymakers, disability sector researchers and advocates. The aim for the day was to identify five key research questions to inform a call for research applications by the Lowitja Institute.

The Lowitja Institute's Program Committees identified disability as a priority area for research in December 2016. This priority was influenced by two factors:

1. Aboriginal and Torres Strait Islander people with a disability are often further disadvantaged by experiences of ongoing systemic racism and ableism.
2. The current government policies, particularly the implementation of the National Disability Insurance Scheme (NDIS), are driving significant change by re-defining interactions and relationships between services and clients. This climate adds to the uncertainty and complexity of an already challenging reality for many Aboriginal and Torres Strait Islander people with a disability.

The scope of the workshop focused on how disability intersects with broader health and wellbeing for Aboriginal and Torres Strait Islander peoples. To do this, the discussions at the workshop pushed beyond the issues and opportunities with the National Disability Insurance Scheme. This encouraged discussions that could potentially guide future research, as well as provide valuable knowledge to communities, policymakers and service providers; leading to better health and wellbeing outcomes for Aboriginal and Torres Strait Islander people with a disability.

This Workshop Summary Report will detail the final research questions that came out of the day by outlining the process and structure of the workshop, highlighting the three overarching principles and themes of the day, that were most evident in discussions, and finally how the five questions related to these concepts.

Process to develop final research questions

This section outlines the sessions of the day, and how they contributed to the development of the research questions.

The day was structured around three sessions which ultimately led to the development of five research questions. During the first session, participants had a general discussion about enablers and barriers in the context of disability and its impact on Aboriginal and Torres Strait Islander people. This allowed participants to consider and share what works, what doesn't work, and what might work in the future.

In the second session, the discussion was structured around priority areas for research. The facilitator asked participants to consider Who, What, When, Where, and Why research questions should be addressed. During these two sessions, participants were also asked to individually write their own key priority areas on post-it notes.

This exercise helped to ensure that all voices were heard, which led to the identification of three key themes, and some overarching principles that were prominent and agreed upon by the participants (outlined in [Section 4](#)). From these themes, participants broke into small groups and worked together to develop 3-4 research questions to share with the larger group. Participants shared their research questions and rationale to the wider group. After this, participants voted on those questions which they thought were most appropriate and effective to inform a call for research applications. The final five questions (discussed in [Section 9](#)) were:

1. How can Aboriginal and Torres Strait Islander communities be practically empowered and resourced to provide disability services and supports through local Aboriginal workforces and organisations? **(12 votes)**
2. How do we increase the leadership of Aboriginal and Torres Strait Islander people with a disability, families and advocates? **(11 votes)**
3. Tell me about your life: what supports/services have you accessed that have improved your life? What services haven't worked? What were the differences before and after the NDIS? **(10 votes)**
4. How can spiritual and cultural knowledges be optimised in a metric based decision-making evaluation framework? **(9 votes)**
5. How do Aboriginal and Torres Strait Islander people with a disability define "success"? **(8 votes)**
 - Within how they choose to self-identify
 - In living in harmony, family, community

Overarching principles during the day

This section outlines each of the three overarching principles that were agreed upon by the participants, and briefly discusses the general themes that grouped the priority areas, which will be explored in more depth later in the report. The overarching principles are:

1. Cultural safety
2. Self-determination
3. Rights based approaches.

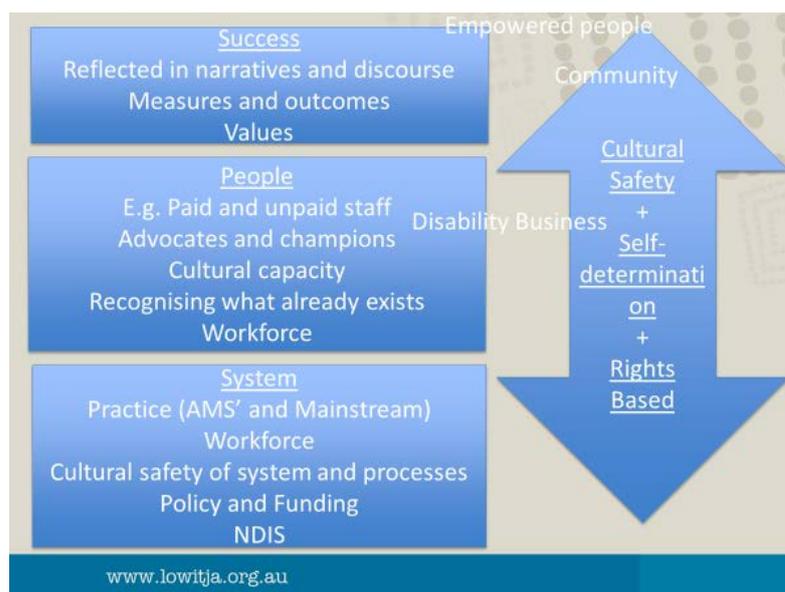
These principles encompassed the key considerations for every discussion of the day, and were overarching to the three general themes that grouped the priorities as they were interconnected to all themes and points of discussion. The general themes can be summarised as:

1. [Success](#) and how it is defined by Aboriginal and Torres Strait Islander people with a disability
2. [People](#) including the workforce, advocates, and paid and unpaid supports
3. [System](#), specifically Aboriginal Community Controlled Health Services compared to mainstream services, the policies (including the NDIS), and funding.

Figure 1 outlines these three themes and general principles as summarised by the facilitators and participants on the day.

The general principles in the arrow on the right of Figure 1, were not given their own individual table for smaller group discussion because they were seen to be overarching and interrelated with each of the three themes. Participants were asked to consider these in their discussion, and this was evident in the research questions that were shared, as many considered cultural knowledge, cultural competency frameworks, and Aboriginal and Torres Strait Islander definitions (a way of exercising self-determination) in their final questions.

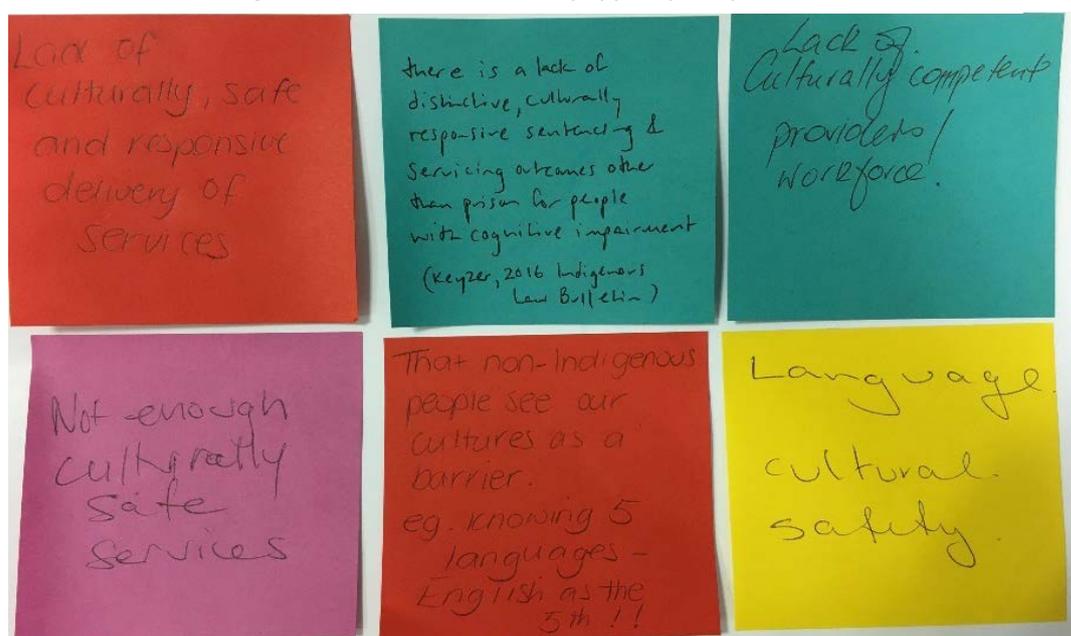
Figure 1. Themes and Overarching Principles



Cultural safety

Cultural safety, cultural competence and its related aspects were a common theme of discussion, especially in the individual feedback on post-it notes as shown below in Figure 2. It was prominent in relation to the cultural responsive delivery of services and a culturally competent workforce. Cultural safety was however, generally considered something that went across discussions about defining *success*, valuing *people*, and unpacking our understanding of the *system*.

Figure 2. Comments on Cultural Safety from participants



Self-determination

Self-determination was discussed in multiple contexts that cut across the three key themes. It was discussed in a political context at the system level, and the need to have Aboriginal and Torres Strait Islander people with a disability in the ‘decision-making room’. It was noted that “*we don’t have enough leaders who have a disability or Indigenous standing*” in this field, and there was consensus that this needs to be addressed. Without this, political decision making can’t be done in the spirit or actions of self-determination. Another participant highlighted the importance of making sure those voices were in the room:

“complete self-determination doesn’t happen overnight, but we need the voices in the room to force decision makers to realise there are risks [in it], but there are BIG opportunities.”

Self-determination also came into conversation about the definition of what success looks like according to Aboriginal and Torres Strait Islander people with a disability. The facilitator summarised the group’s discussion about the interconnection between who defines success and self-determination by responding to the question ‘who defines success’:

“if we consider it is the person with a disability who defines success, then, [it must be] Aboriginal and Torres Strait Islander people with a disability defining success at the Canberra level.”

The overall discussions surrounding self-determination were put to the question ‘how do we make self-determination real?’ and the answers were considered to revolve around voice, leadership, decisions, and power. Self-determination at the individual level was often linked to rights and creating awareness of how to assert the rights that an Aboriginal and Torres Strait Islander person with a disability is entitled to.

Rights

Most of the discussions surrounding rights revolved around awareness, and the need to make sure that Aboriginal and Torres Strait Islander people with a disability and their families know what they are entitled to. One participant stated:

“There is a need for awareness around non-discriminatory practices. Not just by services but within our own communities, and working within a human rights framework, upholding the rights of people with unique and complex needs – whatever they may be”

Another participant felt the need to understand one’s human rights was essential so that they could assert themselves and ensure their rights were being respected. The participant stated:

“...we have to get our people to understand their human rights and assert them. We need to get people saying, ‘no, don’t build me that house because you’re not allowed to do that’. That is a massive gap, people being able to assert themselves when they come up against the system”

The topic of rights, including the Disability Discrimination Act, a lack of knowledge about rights, and violations, also came up in the individual post-it note feedback.

Key Priority Area 1: Defining success, its measures and outcomes

This section outlines the discussions of the day regarding the theme of success, including the definition of success, the connection to self-determination and leadership, the desire to change or shift current mindsets, and the need to share success in these areas through stories.

There were no clearly identified answers or solutions as to what success in the disability area meant for Aboriginal and Torres Strait Islander people with a disability. A question about the definition of success in this space was one of the highest voted research questions, highlighting its importance in this context and discourse. One participant suggested that perhaps success wasn't necessarily about finding solutions to access the flawed system, rather it could be about proposing an alternative:

"[its] not about access to a flawed system, but about a paradigm to a 'new' way of thinking"

The discussion about success is linked to self-determination, and it was widely accepted that the definition of success in this space needed to be achieved by Aboriginal and Torres Strait Islander people with a disability. But, it was also noted that success in this field benefits the wider Aboriginal and Torres Strait Islander community, and the wider Australian population. Simply, success in this space can, and will benefit everyone.

The discourse about changing mindsets, attitudes and the general understanding of disability was embedded in a discussion about success. The participants proposed that the two best ways to achieve this change are:

1. Leadership from Aboriginal and Torres Strait Islander people with a disability.
2. Storytelling.

The idea of leadership came from concepts of empowering or instilling greater confidence in Aboriginal and Torres Strait Islander people. One participant stated that success comes from:

"...building the resilience of individuals and communities, also attitudinal change around empowerment of people with disability"

The need to encourage and foster the potential of Aboriginal and Torres Strait Islander people with a disability came across quite strongly. Many noted that when people with a disability aspire about their future and participate in goal setting, then success is achieved. One participant stated that:

"It is about shifting people's mind set. [It] goes to attitudes, recognising potential of people"

To recognise the potential of Aboriginal and Torres Strait Islander people with a disability, opportunities need to be highlighted. Participants believed that this is best achieved through storytelling, and sharing positive examples of success and accomplishment. One participant thought:

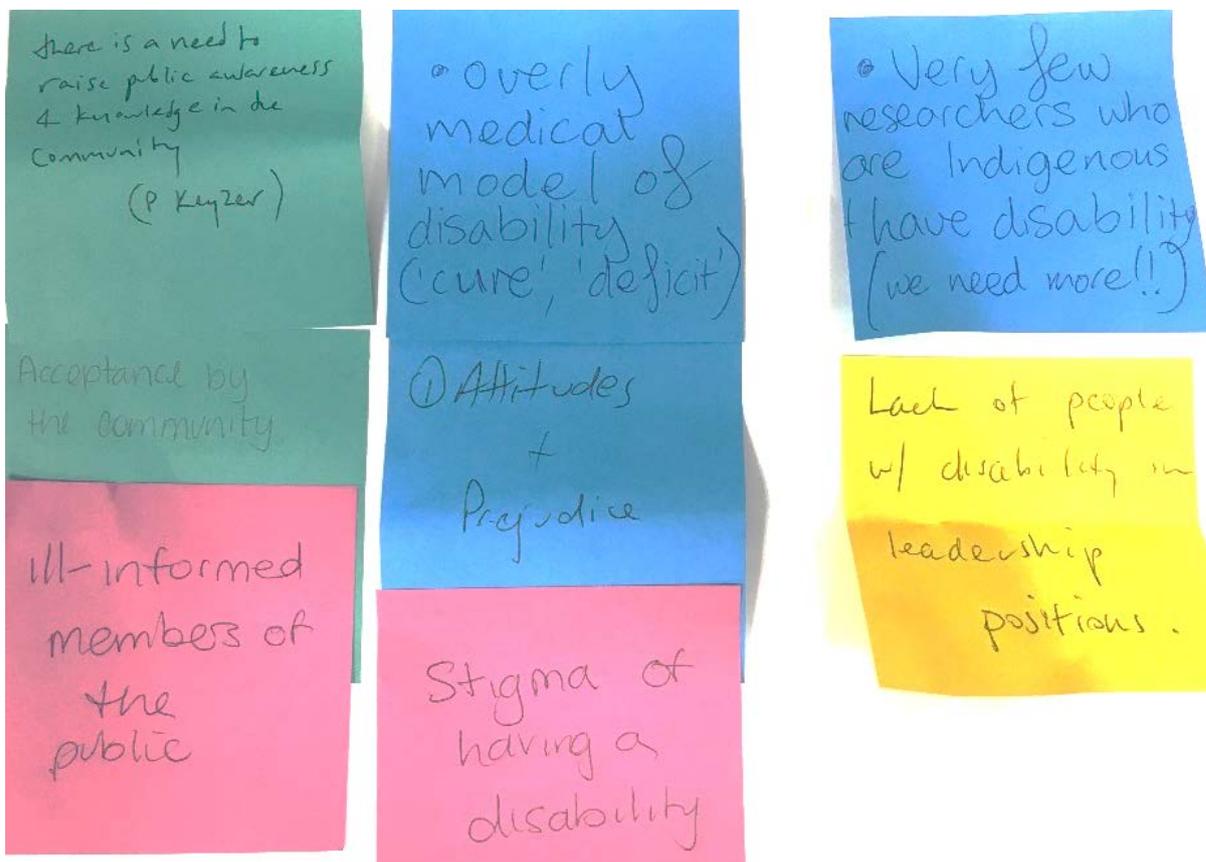
"stories of success are a really crucial tool to capturing that success"

This connection between leadership and success came across strongly in both the large and small group discussions. During the small group discussion, participants talked about the visual elements of Aboriginal and Torres Strait Islander culture, and the need for young Aboriginal and Torres Strait Islander people with a disability to have relatable role-models that inspire them

towards achieving their goals and demonstrating leadership. That leadership could be in the form of politics, service delivery, meaningful employment or community.

The discussions about noticing and changing attitudes or mindsets, creating greater awareness, and the need for demonstrated leadership from Aboriginal and Torres Strait Islander people with a disability also came across in the post-it notes, as demonstrated in Figure 3.

Figure 3. Participants' comments on attitudes and leadership



Key Priority Area 2: Valuing people and giving them the best resources to succeed

This section will outline the discussion about people, specifically valuing the people ‘standing beside the mob’, the difference between paid and unpaid supports, and empowering people within the system, and providing adequate resources.

There was an initial discussion about the need to value those carers and support people ‘standing beside the mob’. This discussion advanced throughout the day and included consideration of how to acknowledge and properly resource these people. There was a strong consensus that the workforce, the expertise and the people who are best equipped to support Aboriginal and Torres Strait Islander people with a disability are already in communities. One participant noted that these people didn’t stand beside Aboriginal and Torres Strait Islander people for a financial gain but for other reasons:

“...they are unofficial practitioners in communities and families, and they do it for so many other reasons- not always a financial gain, but because of their commitment to their community, their mob and their families...[and] they come with all the expertise that exists within those communities and families”

There was a general discussion about the difference between the community supports (that is the unpaid carers) and the paid support people. Participants widely agreed that there was a strong need to better embrace, support and resource the cultural or community workforce. One participant stated:

“There are those formal ones and then the cultural workforce. One is remunerated and recognised and the other isn’t. The volunteers are worthy of being the ‘down trodden’ component of the entire practice base. Thinking about it as a practice community rather than individual members of a workforce would be worthy of considering”

Figure 4 depicts how the facilitator summarised the group’s discussion about valuing the people who are ‘standing beside the mob’.

Figure 4. People to Stand Beside the Mob

- People to Stand Beside the Mob**
- Natural helpers e.g. family, Elders, carers
 - Need some professional development, skills
 - Recognition
 - Remuneration
 - Voice
 - Value and empowerment/support
 - Employment services are appropriate -> wellbeing
 - Removing ‘cash only’ motivation

As outlined, there was a strong emphasis on the fact that there is already a workforce that exists, which needs to be acknowledged as a strong enabler. In line with this thinking, is that resources

should be focused on this workforce, rather than external services or supports. Some participant quotes about this are below:

“The workforce is already there, and one of our great enablers is that we have people, and people who are responsive.”

“We place too much focus on bringing people who specialise in, when the specialists are already there – they just need the support and resources.”

There was also a discussion about the need to empower people within the system or in decision-making positions to advocate and be change makers in this area. One participant called for a need to:

“empower people within systems to transform systems. Move people outside of being comfortable. [They] have to be advocates, disruptors, prosecuting ideas that have incorrect assumptions”

This discussion about empowering people within the system was also connected to having people standing beside the mob. These people also need to be there with Aboriginal and Torres Strait Islander people with a disability when they are facing the wider system. One participant stated that:

“We have to have people standing beside the mob, and help them through and support when they come against the external system”

This discussion about valuing Aboriginal and Torres Strait Islander people with a disability, especially when considering the external system, raised questions about what benefit is achieved when services are delivered by Aboriginal and Torres Strait Islander organisations, or mainstream services. This led to comments from participants that suggested mainstream services could potentially be appropriate, provided their cultural safety was improved significantly. However, participants stated that if funded properly, Aboriginal and Torres Strait Islander organisations would be the ideal services to be standing next to the mob.

Key Priority Area 3: Understanding the system- what works, what doesn't

This section outlines the discussions about the system, including a general overview, the need for them to be culturally safe and properly resourced, have a design of flexibility as opposed to a 'one-size-fits-all' model, to be accessible, and to be accountable for their impact on the lives of Aboriginal and Torres Strait Islander people with a disability.

There were discussions about the system at the policy and decision-making level, at the delivery level, and regarding funding and outcome measurement. This theme was a popular topic, especially for the individual post-it note exercise, as demonstrated in Figure 5.

Figure 5. Participants' comments on the system



There was a consensus that the system and services needed to be culturally safe, and that currently this was lacking. There was also agreement that there should be a role for Aboriginal and Torres Strait Islander organisations in the delivery of disability specific services, and potentially within the NDIS space, due to their strong cultural protocols. However, this was under the strong condition that these organisations needed to be better resourced and funded prior to acquiring these additional roles. Regarding funding more generally, participants raised concerns about the lack of 'sustainable' funding, and characterised the current funding as 'inadequate' and 'uncertain' (see Figure 5).

There were general concerns about whether the system was adequate for Aboriginal and Torres Strait Islander people with disability; one participant expressed that, "the system is harming our people". Another participant raised the point about the system not being relevant or appropriate for Aboriginal and Torres Strait Islander people by stating:

"A system developed without the First Nations People from a country without a first nations people is problematic. Our whole culture is on trust and storytelling. Our approach needs to

come from the community and bottom-up. The bureaucratic system that comes down and links First Nations people has never worked in any capacity, whether disability or any other way.”

Participants strongly believed that the system and its services need to be flexible and adaptable to the individual and/or their community. This notion came out in discussions about enabling factors and when considering the system in its entirety. Participants generally felt that Aboriginal and Torres Strait Islander organisations, such as Aboriginal Community Controlled Health Organisations, could better reflect their holistic understanding by drawing on their strengths of embedding culture in the delivery of disability services. It was noted, however, that these organisations were restrained to an extent by the requirement to complete their reports and Key Performance Indicators (KPIs) for funding using government rhetoric and values. That tension between a flexible system and an unadaptable one, was summarised by one participant who stated:

“Systems sometimes fear diversity because they’re looking for a one-size fits all [approach], which is convenient but not for people who stand for the benefit and need to be empowered in their strengths. We’re not all the same, we have different priorities, histories. Some are similar, but we don’t need a one-size fits all response.”

In addition to this general one-size fits all response from government, participants noted that the disability sector, especially related to services, was incredibly siloed and bureaucratic. Such an approach is contradictory to the desired flexible and adaptable one, yet one participant expressed:

“I don’t think there is a more siloed approach in the world than in the disability world.”

Participants also discussed the difficult access to the system, and the burden that was often associated with accessing or engaging disability services. One participant discussed the difficulty that Aboriginal and Torres Strait Islander people have accessing disability services - it takes over their life - which is not the case for people who don’t have a disability. It was also addressed that the difficult access to services for Aboriginal and Torres Strait Islander people with a disability is heightened for those living in a rural or remote community.

“[There are] many people in remote and rural communities who aren’t even on a disability support pension, [they’re] not in a system, and [they] don’t access anything. So, they’re not going to access a service if they don’t even have any money coming in to feed them.”

There was a discussion about how the system needs to be accountable for Aboriginal and Torres Strait Islander people with a disability, and ensure that it helps rather than hinders their life progression. This discussion occurred as participants felt that when an Aboriginal or Torres Strait Islander person with a disability hits the wider system (either education, health or another), that is when their disability becomes a barrier. This has merit with the social model of disability, which understands that society is what disables a person, not their impairment, and that it is society and/or system that needs to change. One participant stated quite succinctly that:

“People have problems when they hit the system...Disability starts when you hit the system.”

This discussion led to a conversation about the fact that the system (in this particular case, school) is often inadequate in catering or acknowledging the disability of Aboriginal and Torres Strait Islander children, which can alter their life trajectory in a negative way. The inability to diagnose a

disability which may be impacting the child's life at school, can lead to that child acting up and going down a negative path due to a lack of support. This was linked to the high rates of Aboriginal and Torres Strait Islander people with an intellectual or cognitive disability in prison. Participants discussed the fact that the system (be it services, health and/or education) were unable to make early diagnosis of certain disabilities, and that had a flow on effect by not providing adequate services to that individual, resulting in greater rates of incarceration. One participant wrote on their post-it note:

“There is a need for early assessment, diagnosis, support and intervention (including in the juvenile justice system) that prevents criminalisation and is capable of identifying and addressing root causes of offending.”

Other important themes

This report details the themes that came out of the discussions on the day around the context of disability and how it impacts Aboriginal and Torres Strait Islander people. Whilst the three main themes are broad and encompass many of the important topics within this space, there were other issues that participants recognised were important (which did not necessarily get a specific focus throughout the day). These were issues around childhood development, and within the justice sector. Although these were not addressed in any detail, they did arise in some discussions (such as justice within the context of systems).

Top 5 voted research questions

This section details the final five research questions, and how they connect with the three principles and three themes discussed in this paper. Whilst the final five questions each came from small group discussions about one of the three main themes: *people*, *success*, and the *system*, they interrelate and encompass the overarching principles of self-determination, cultural safety and rights.

1. How can Aboriginal and Torres Strait Islander communities be practically empowered and resourced to provide disability services and supports through local Aboriginal workforces and organisations?

This question came from discussions about the *system*, specifically Aboriginal Community Controlled Health Organisations (ACCHOS), and local community organisations delivering services. It is connected to the discussions about adequate funding to support these local, flexible and culturally appropriate services. It is also connected to the theme about *people*, the workforce and those standing beside the mob, as it is about empowering and resourcing those people. The principles of self-determination and cultural safety come through in the conceptualisation of this question regarding empowerment and considering the cultural benefit of engaging (ACCHOS) or other local organisations rather than mainstream or external alternatives.

2. How do we increase the leadership of Aboriginal and Torres Strait Islander people with a disability, families and advocates?

This research question came from the small group discussing the *people* theme. It is connected to discussions about low expectations and a need to change attitudes so that young Aboriginal and Torres Strait Islander people with a disability can develop aspirations by viewing similar people they can identify with in leadership positions. It is also connected to the discussions about *success*,

as it proposes highlighting examples of success to facilitate a change in attitudes, and develop confidence so that Aboriginal and Torres Strait Islander people with a disability can aspire to successful outcomes including varying forms of leadership.

3. Tell me about your life: what supports/services have you accessed that have improved your life? What services haven't worked? Before and after analysis.

This question is interconnected to discussions about all three of the main themes of the day. Firstly, it is about valuing the individual Aboriginal and Torres Strait Islander people with a disability, and their thoughts about supports and/or services that have improved their lives. The life improvement element is connected to discussions of *success*, as it asks what has worked and what hasn't work, whilst also prompting potential discussions about what ultimate success is to the individual. Secondly, it considers supports, which may include the workforce and those *people* standing beside the mob in their life whilst navigating the disability space. Finally, it is evidently connected to the *system* and services, by directly asking which ones have or haven't worked. It is connected to a consideration of the NDIS, and a before and after analysis, but it also goes beyond that and seeks to consider all services and supports accessed (or not) during an individual's life.

4. How can spiritual and cultural knowledges be optimised in a metric based decision-making evaluation framework?

This question is about the *system*, especially in relation to decision-making and the need to better value Aboriginal and Torres Strait Islander knowledges. It ponders how to make concepts and values that are important to Aboriginal and Torres Strait Islander people quantifiable so that they fit the metrics required by the system for funding and other outcomes. This discussion is linked to self-determination and how to make the current non-Indigenous system more open to self-determined measures of success and outcomes.

5. How do Aboriginal and Torres Strait Islander people with a disability define "success"?

- **Within how they choose to self-identify**
- **In living in harmony, family, community**

This question about *success* largely encompasses one of the major points that occurred throughout the day. As previously discussed in [Section 5](#), success can be defined in any number of ways as it is related to success in general, success in the system, and/or success for the individual. The need to define success as it relates to Aboriginal and Torres Strait Islander people in the disability space impacts everyone and is connected to principles of self-determination and rights, and cultural safety by ensuring it is relevant and appropriate.

Next steps

The Lowitja Institute has developed a research funding application process, based on the identified research priorities listed above; funding to be announced in early 2018 and projects completed by May 2019.

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