



'NO MORE WAITING'

A guide for organisations to plan with Aboriginal people with disability

Acknowledgements

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“No More Waiting”: A Guide for Organisations to Plan with Aboriginal People with Disability was developed through a collaborative process involving 25 Aboriginal people from three rural and two metropolitan communities in New South Wales (NSW) working with researchers. Participants included Aboriginal people with disability, family members and support workers. Community mapping workshops were held to find out people’s experience of planning. This organisational planning guide was informed by participants’ insights into the unique histories, values, traditions, and stories which define their communities’ identity, connections and sense of place, and lived experiences of planning. The title of this guide: *“No More Waiting”* came from a workshop participant and indicates the frustration Aboriginal people feel about planning and getting access to supports and services.

Cover Artwork

UNSW Sydney acknowledges Jason Brown, a proud Ngarabul man, whose artwork *“No More Waiting”* appears on the front cover and throughout the document. The painting represents Jason’s concept of disconnection between disability services and Aboriginal people and families who need those services to live well in remote, rural and urban communities. The white circles depict the services with Aboriginal people sitting around waiting for those services to engage with them and work collaboratively. The grey area at the centre of the painting shows that the process of accessing and receiving disability services is not clear and lacks transparency.



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About the Planning Guide

This planning guide is intended to provide organisations with information to assist them to be ready to engage with Aboriginal and Torres Strait Islander people with disability and their families in planning for social care. Throughout this guide the word Aboriginal refers to the First Nations people of Australia, and we acknowledge that Torres Strait Islander people are among the First Nations of Australia. This guide is designed for workers in organisations who are committed to working with Aboriginal people with disability in culturally respectful ways.

In this guide we use the terms 'Aboriginal-led' and 'non-Aboriginal-led' organisations. These terms differentiate organisations led by and with a primary focus on providing services to Aboriginal and Torres Strait

Islander people (Aboriginal-led) from those which provide services to the broader community, including Aboriginal and Torres Strait Islander people (non-Aboriginal-led).

Aboriginal people with disability and their family members may also find this guide helpful to use in conjunction with individual planning resources, some of which are mentioned in section four of this guide.

The development of this guide is in response to recognition that Aboriginal people with disability and their family members may be unfamiliar with formalised planning processes and may require more intensive, coordinated, and culturally appropriate support.

The guide is divided into four sections:

SECTION 1: defines what is meant by planning

SECTION 2: describes how disability is different for Aboriginal people and identifies some barriers to engaging in planning

SECTION 3: describes Our Ways to planning for Aboriginal people with disability and family members through the Three Bridges Approach

SECTION 4: provides some useful resources and references

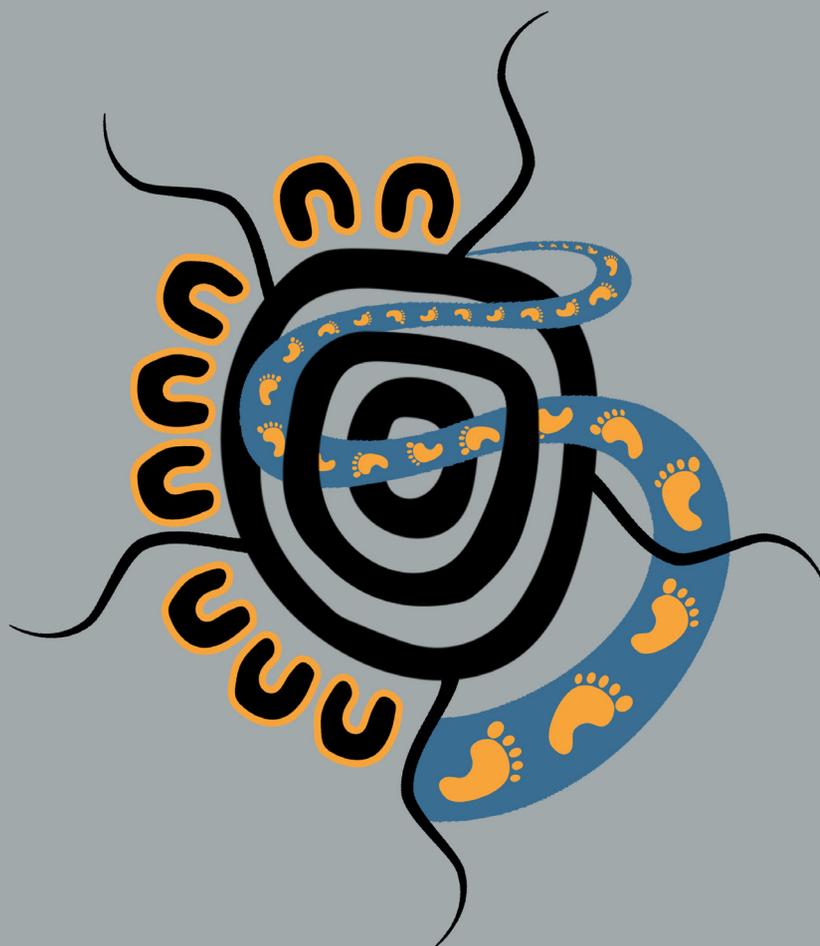
Throughout the guide, the words and artwork of the twenty-five Aboriginal people who participated in community mapping workshops in New South Wales, Australia are included to show how the guide was informed by their experiences.

SECTION ONE:

What is meant by planning?

All people set goals and make plans for future activities and aspirations but not all planning is formalised. Planning with people with disability has become a formal process with person-centred planning at the heart of contemporary service delivery across disability, health, education, employment, and community sectors. Planning is central to identifying the goals and aspirations of people with disability. Done well, planning provides opportunities for identification of capacity, risks and safeguards to enable the right mix of supports and services for the person to achieve his or her goals. Person-centred planning is a way for people to say what they want and need and work out how to achieve their goals.

Many Aboriginal people may not identify, and be uncomfortable with this individualised approach, instead they may see their identity as inextricably bound with family, community, and culture. Culture is at the centre of social and emotional wellbeing for Aboriginal people. This means that planning with an Aboriginal person with disability must be family, community and culture focussed and based on how the person views him or herself and is viewed by others, including family, community, and broader social and cultural connections.



This image is adapted from the community map of the Durri Aboriginal Corporation Medical Service, Kempsey and Biripi Aboriginal Corporation Medical Centre, Taree. It represents the journey of an Aboriginal person with disability to make a plan.

1.1 Pathways to Planning

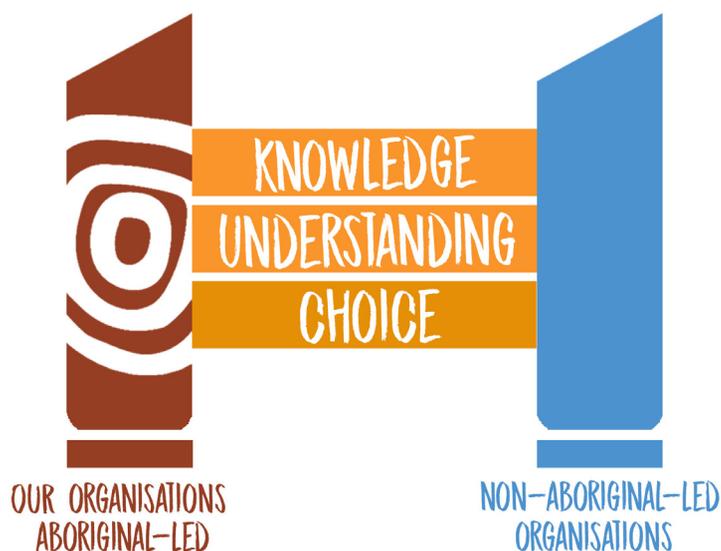
This guide identifies a culturally appropriate, collaborative and inclusive approach to planning with Aboriginal people with disability, family and community.

The guide is based on recognition that Aboriginal people often experience high rates of disability but access few supports. These low access levels may be due to a combination of factors such as socio economic disadvantage and geographic isolation. Aboriginal people with disability often wait longer to receive supports and services and may experience specific barriers to engaging in planning resulting in culturally inappropriate planning outcomes. An alternative approach to planning is suggested in this guide which embraces and builds upon the many strengths of Aboriginal people, their communities and organisations.

Collaboration aimed at bridging the divide between Aboriginal people with disability, their family members and communities with organisations can result in alternative and meaningful ways to engage in planning so that the goal of 'no more waiting' is achieved. A collaborative approach builds the capacity of Aboriginal people with disability, their families, communities and organisations.

The collaborative approach is based on the three bridges of:

- 👣 knowledge through information and advocacy
- 👣 understanding through cultural respect, awareness and training
- 👣 choice through Aboriginal and Torres Strait Islander-specific supports



1.2 Stages of Planning

Previous person-centred social care planning research identified that there are three stages to planning:

STAGE 1: PRE-PLANNING

This first stage involves the organisation's worker who is assisting a person with disability to make a person-centred plan gathering background information to get to know the person, their family and community, and identifying the resources that might already be available in their current environment and context.

 *For Aboriginal people with disability this may include spending time with the person and their family in their community, understanding past experiences with disability and community services, and how this may impact on future engagement.*

 *Ask the person to "Tell me your story . . ."*

For more detailed information about this planning approach, visit the UNSW Intellectual Disability Behaviour Support program website: arts.unsw.edu.au/idbs/support-planning

STAGE 2: PLANNING CONVERSATIONS

The second stage involves planning conversations where the person with disability, their family and community along with the planner discuss the person's capacity and identify risks and safeguards to come up with a person-centred plan with short, medium and long term goals to help ensure the person with disability had a good life now and in the future. It is important to find out who in the community is involved in these practices and activities and develop connections with them.



For Aboriginal people with disability this may include supports and services to facilitate the person's engagement in valued cultural practices such as caring for Country, community gatherings, learning cultural knowledge and language, participating in arts, craft and sport; as well as therapy, equipment, medical care, aged care, education or employment, social activities and so on.



Ask the person "What do you like to do?"

STAGE 3: PLAN TO ACTION

The third stage is where the plan created in stage two is implemented taking into account ways to build the person's capacity and pre-empting problems by identifying safeguards/strategies to overcome any risks. Capacity and safeguards work in tandem, so the person with disability can achieve his or her goals.



For Aboriginal people with disability this may include strengthening relationships with Aboriginal-led organisations and drawing on people and resources both within and outside those organisations to support the person in culturally appropriate ways. It may also include identifying things that may get in the way of the person achieving his/her goals and making contingency plans in case this happens.



Ask the person "What has worked well in the past?"

SECTION TWO:

How is disability different for Aboriginal people?

FACT: Aboriginal Australians are more than twice as likely to experience disability compared to non-Aboriginal people. ¹

Aboriginal people's experience of disability can be quite different to that of other Australians. These differences, which affect how to plan with an Aboriginal person with disability, may be attributed to five key areas:

-  Lack of identification of disability
-  Experience of multiple disadvantage
-  Feeling shame and feeling judged
-  Lack of trust
-  Complexity of issues

2.1 Lack of identification of disability

FACT: Many Aboriginal people with disability do not identify themselves, nor are they identified by other Aboriginal people as having a disability.¹³

Aboriginal languages have no word for 'disability'; instead people describe the effect of the disability; for example, "he has a bit of trouble getting around", "she doesn't hear too well", or "that is just the way he is".

What does this mean for planning?

While not labelling a person as 'disabled' may mean he or she is less likely to be identified and discriminated against, it also means that the person and their family members may not plan for supports and services that may help them in their everyday lives.

What can your organisation do when planning with a person?

-  *Don't rely on medicalised terms to ask people about their disability. People often won't recognise or identify with these terms. Instead ask "tell me your story" to gain a better understanding of the person's holistic experience of disability as part of their life. Also ask "tell me ways we can help you" to encourage people to think about what will make their life better.*
-  *Offer suggestions and give practical examples of the kind of help available so that people who have "a bit of trouble getting around", don't "hear too well", or "just may be that way" can plan for access to supports and services that may help them like a mobility or hearing aid, or personal care.*
-  *Frame the plan in terms of what will make the person's life better/easier now and in the future rather than making the person feel labelled.*
-  *Discuss how, by making plans to get additional support for the person with disability, the whole family may feel less stressed even though people may not recognise they are stressed. The extra support may mean family members will have more time to do other things.*

2.2 Experience of multiple disadvantage

FACT: Compared to the overall Australian population, Aboriginal people experience poorer health, earlier deaths and higher rates of child mortality, lower levels of education and employment, higher rates of incarceration, and lower standards of living.³

Many Aboriginal people with disability and their carers have experienced trauma, loss, grief, violence, anger, chronic illness, and disadvantage throughout their lives. Aboriginal people who identify as having a disability may experience multiple disadvantage associated with their disability and their Aboriginality, resulting in stigma and discrimination. Experience of stigma and discrimination are associated with physical and mental ill health, loneliness, and reduced quality of life.

What does this mean for planning?

An Aboriginal person with a disability is likely to encounter additional barriers in planning to access services such as health, education and employment due to their disability as well as their Aboriginality. This might mean the person and their family may not mention, or may try to hide the disability as much as they can. Misconceptions and stereotypes about Aboriginality can result in a person's disability being overlooked. It may also mean that young Aboriginal people with disability are discouraged from making plans related to education and employment and developing interests and activities. Being an Aboriginal woman with a disability may present additional planning barriers to a girl or woman's participation and inclusion due to sexism.

"As an Aboriginal woman I live in two worlds; the Aboriginal world and the broader world. Aboriginal people with disabilities have learned to live in three worlds; Aboriginal, broader, and disabled worlds. This is a real challenge."

What can your organisation do when planning with a person?

-  When engaging in planning, ensure that your organisation is aware of the potential presence of multiple disadvantage and the experiences of exclusion this can cause across multiple settings.
-  Review and if necessary, revise your organisation's policies and procedures so they are inclusive of Aboriginal people with disability.
-  Brainstorm ways to ensure that your organisation actively encourages Aboriginal people with disability (especially young people, women and Elders) to be included and supported in planning and access.

2.3 Feeling shame and feeling judged

FACT: Having a disability or being the carer of someone with a disability may be a source of shame for families when asking for help. ¹⁵

Aboriginal people with disability and their family members may be in denial of the disability because not enough is known about it. People may feel shame asking for help especially when the disability is attributed to Foetal Alcohol Spectrum Disorder (FASD) or an acquired brain injury due for example, to alcohol and other drug misuse, violence, or a motor vehicle accident.

What does this mean for planning?

Aboriginal people with disability and their carers may not engage in planning because they feel shame when asking for help. Carers may try to 'do it alone' because they feel responsible for the person. Carers and the wider community also may not understand that although an intellectual or cognitive disability cannot be fixed and is permanent, there are supports available.

"A big issue that needs addressing is the way years of negative representation of Aboriginal people, and negative stereotyping has led many Aboriginal people to think that they are inferior to others, not worthwhile, not capable of good things."

What can your organisation do when planning with a person?

-  Provide Easy Read information about the nature of the person's disability and encourage a culturally appropriate discussion about this issue.
-  Model inclusive and non-judgemental attitudes towards Aboriginal people with disability and encourage others to do the same in the planning process.
-  Be realistic about people's short, medium and long term goals and communicate this in a sensitive way.

2.4 A lack of trust

FACT: A lack of trust in non-Aboriginal organisations means many Aboriginal people are reluctant to engage with planners, workers, services and formal supports.¹²

Aboriginal people's distrust of non-Aboriginal organisations is based on past and present experiences of discriminatory, controlling, and exclusionary policies and practices such as the Stolen Generation, Royal Commission into Aboriginal Deaths in Custody and the Northern Territory Intervention.

What does this mean for planning?

An Aboriginal and Torres Strait Islander person may not acknowledge that they or someone they care for has disability in fear of the consequences. People are also concerned that letting planners (and workers) into their homes will result in negative judgements about them and may lead to interventions they do not want. People may ignore phone calls and messages left from private numbers they do not know and may refuse to let people into their home unless they are identified and expected.

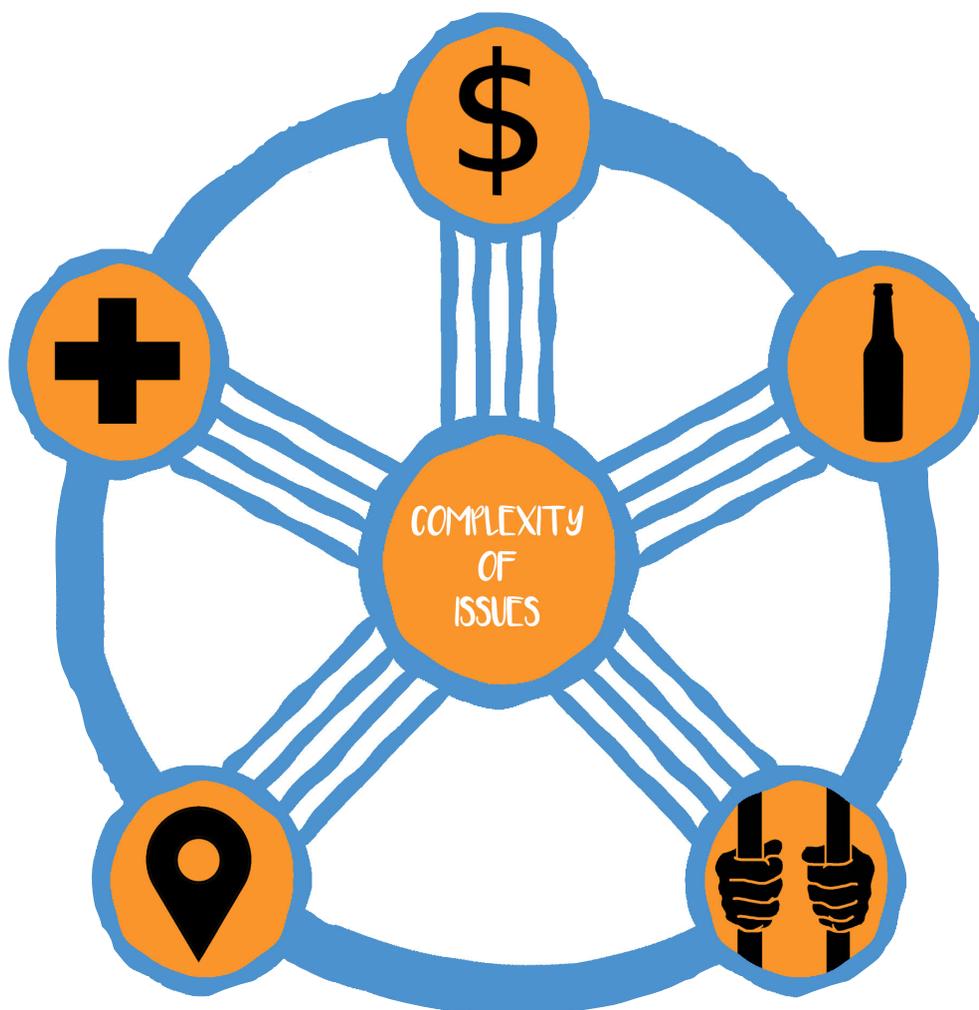
What can your organisation do when planning with a person?

-  *Establish connections between Aboriginal-led and non-Aboriginal-led organisations and assist each other to develop policies and practices that build trust such as holding community events together, or participating in significant Aboriginal events such as NAIDOC and Sorry Day.*
-  *Ensure that in the pre-planning stage, adequate time is committed to building relationships with people and communities as an integral part of planning.*
-  *Create safe spaces around planning for Aboriginal people to share their stories. Consider where and how planning is conducted (e.g., an office may not be the best place to hold the planning conversations if the organisation is co-located with Child Protection, Police, or Centrelink services, as this may exacerbate people's concerns about engaging).*
-  *Respectfully acknowledge the past and how it impacts on the present and planning for the future for Aboriginal people.*
-  *Hire Aboriginal and non-Aboriginal planners who are culturally aware and trusted within Aboriginal communities and encourage them to lead the work of building capacity of non-Aboriginal workers and building trust for Aboriginal people with disability and family members.*

2.5 Complexity of Issues

FACT: Complexity relates to the multiple, interlocking experiences and factors that span Aboriginality, disability, behavioural and social issues over the life course.⁵

Complexity can result from individual life situations and the failure of services and other supports to respond appropriately when needed and over time. For Aboriginal people with disability, complexity comes from a range of often inter-related factors with some of the main ones being: socio-economic status and unemployment, geographic location, experience with the health system, substance misuse, and experience with the criminal justice system.



Socio-economic status and unemployment



There are high rates of unemployment among Aboriginal people and a lack of employment opportunities especially for Aboriginal people with disability. 1

What does this mean for planning?

Aboriginal people with disability and their family members may experience lower economic status because they may rely on Disability and Carer payments due to restrictions on their ability to participate in the workforce. Accessing supports and services to assist the person with disability can also be expensive and a lack of money may mean people do without basic necessities. These factors are very important to consider when planning with the person.

"People who have a job, even if it is part-time, are lucky. There are lots of drugs coming into town from everywhere and lots of unemployment."

What can your organisation do when planning with a person?

-  *Include in planning conversations the full- or part-time employment opportunities that might be available for the person with disability (and family members) and any training that they may require to gain employment.*
-  *Check that people have the basics they need to engage with planners (e.g., credit on their phones to return planner's calls).*
-  *Ensure planners can provide information to people about the range of financial supports available to Aboriginal people with disability and carers and how to apply or get assistance to apply if needed.*
-  *Respect the role of Aboriginal workers who may be facilitating the planning process with the person or seek advice from an Aboriginal worker.*

Geographic Location



Aboriginal people with disability living in geographically rural and remote communities experience a lack of culturally appropriate and responsive services and need to travel to services and supports located in larger regional or city centres. 8

What does this mean for planning?

Additional costs to access supports include travel, fuel, food and accommodation for the person with disability and family members. Often logistical issues such as the lack of a vehicle or accessible transport can act as a serious barrier to people accessing services. Within very geographically remote Aboriginal communities, access to fresh and nutritious foods and refrigeration to keep food and medicines at required temperatures, can also be an issue. When planning with Aboriginal people from rural and remote communities these issues should be discussed and accommodated within the person's plan.

"There is no (public) transport and getting anywhere costs a lot for petrol especially when we have to travel to (other towns) to get services that are not here in (this town)."

What can your organisation do when planning with a person?

- If you are planning with an Aboriginal person with disability and family members in remote and very remote communities, identify innovative options for access to supports and services in the local community rather than expecting service users to travel. For example, local people employed as therapy support workers who implement interventions developed and overseen by therapists based in larger centres.*
- Consider how local Aboriginal people (including those with disability and family members) can be employed, trained and supported to provide services and supports within their community.*

Experience with the health system



Aboriginal people with disability and carers may be frequent users of the health care system due to both chronic and acute physical and mental health needs. 3

What does this mean for planning?

Accessing health services may be difficult for many Aboriginal people with disability and carers due to a range of factors including: lack of identification of disability, communication and language barriers, medical terminology used by health professionals, experience of racist attitudes leading to a lack of trust, lack of understanding by the health system of family structures and responsibilities, multiple complex physical and mental health issues, lack of transportation and cost of travel. When planning for the physical and mental health and wellbeing of an Aboriginal person with disability, these issues should be considered.

"Sometimes it's hard to get GPs and other medical people to agree to what the person has in their plan. If they don't agree to the plan, you can't get it approved."

What can your organisation do when planning with a person?

-  *Talk with the person and their carers about physical and mental health – do they have chronic and/or acute health problems they could be treated for?*
-  *Try to understand what might underlie the person's reluctance to use a community or hospital-based health/mental health service. Include ways to overcome this obstacle in a person's plan. For example, include using an Aboriginal Medical Service; accessing Aboriginal Hospital Liaison Officers or Workers; accessing Aboriginal Health Education Officers or Aboriginal Health Workers in Local Health Districts; and Aboriginal Health Practitioners in private GP practices.*
-  *Identify ways to overcome communication and language barriers such as having the person attend a health/mental health service with someone who knows their communication style and preferred language and by providing Easy Read and pictorial health/mental health information to explain medical/clinical terms or with assessments and providing results.*
-  *Including genograms (visual maps of family and community structures) in the person's plan to educate health/mental health services about the importance to physical and mental health and wellbeing of Aboriginal family structures and relationships.*

Substance Misuse



Some Aboriginal people with disability have acquired their impairment through misuse of alcohol, cannabis (yarndi), inhaling petrol and other solvents, and methamphetamines (ice).

What does this mean for planning?

Misuse of these substances may lead to an acquired brain injury or engagement in risky behaviours that result in traumatic brain injury. Aboriginal people who acquire their disability from misusing substances may experience stigma and shame and risk contact with the criminal justice system. Planning is especially complex with people for whom substance misuse is chronic.

What can your organisation do when planning with a person?

-  *Develop Easy Read culturally appropriate materials with information about alcohol and other substances for use in planning conversations.*
-  *Talk about how the use of substances and risk of contact with police, courts and prisons may impact on the person's plans for the future.*

Contact with the criminal justice system



The rate of contact with the criminal justice system for Aboriginal people, and in particular young people with cognitive disability and/or mental ill-health, is considerably higher than the national average. 2

What does this mean for planning?

Aboriginal people with mental and cognitive disability are significantly more likely than non-Aboriginal people to come into contact with police, courts and prison from an early age often because culturally appropriate interventions are not considered or available in their communities. Once young Aboriginal people with disability have contact with the justice system and are not properly supported, it may be difficult to plan for change as adults.

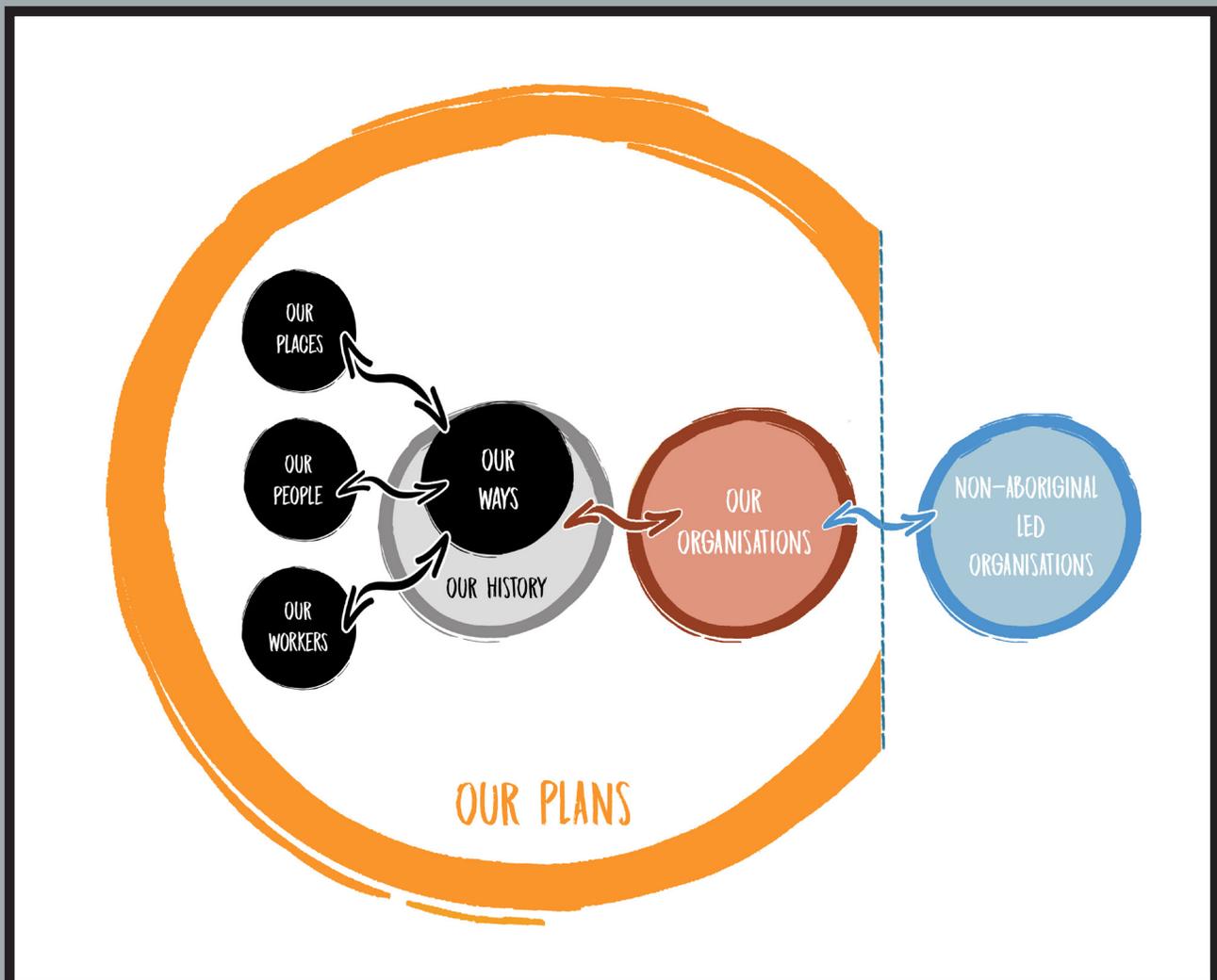
What can your organisation do when planning with a person?

-  *Within the planning conversations, discuss a range of activities and events that may engage the young Aboriginal person with disability in developing interests, skills and passions that may divert them from coming into contact with the criminal justice system.*
-  *If engaged in planning with Aboriginal people with disability who are already in contact with the criminal justice system, discuss with the person and their family the involvement in the planning process of local police (through the Aboriginal Community Liaison Officer), probation officers, lawyers and court officials so alternatives to detention and prison are part of the plan.*

SECTION THREE:

Our ways to planning

Aboriginal-led (Our) Organisations are more likely to understand the historical context underpinning culturally informed planning represented by Our Ways, Our Places, Our People and Our Workers. The diagram below reflects many Aboriginal people with disability and carers' current experiences of planning. Non-Aboriginal-led organisations are represented outside the Our Plans circle with a blue dotted line showing a disconnect between them and Aboriginal-led organisations. The disconnect is due to a perceived lack of understanding by non-Aboriginal-led organisations of the context of planning for Aboriginal people. The disconnect means that some Aboriginal people with disability and carers may wait a long time for or miss out on the full range of supports and services they could be accessing through their plans. In the planning process it is important to be aware of Aboriginal people's experience of history and culture. These issues are explored in the following section.



3.1 Our History



Understanding the impact of the historical, and ongoing, colonisation of Aboriginal people is fundamental in order for organisations to engage in planning with Aboriginal people and their families. Ongoing colonisation is experienced through:

- 👣 Past and present government policy (e.g., lack of recognition of the human rights of Aboriginal people as demonstrated by segregation, assimilation and intervention policies)
- 👣 The ongoing impacts of the Stolen Generations on people's identification and connection with parents, grandparents and siblings, and with community, culture, and Country
- 👣 The tensions caused by forced resettlement onto missions and putting together of different Aboriginal groups with different languages and customs
- 👣 Past and present experiences which may result in intergenerational trauma

“I’m one of the stolen generations, I don’t feel comfortable when government people come to my house. Workers and planners need to understand the impact of history on people with disability and their carers, they need to understand intergenerational trauma”

3.2 Our Ways



Aboriginal people and organisations have many strengths related to shared knowledge (e.g., languages, terminology, and view of disability), and shared ways of being (e.g., inherent trust built over time). There is also great diversity across Aboriginal communities with different mobs, different ways of doing things, and different life experiences.

Sometimes due to government policy and other factors such as work, education or family ties, Aboriginal people may live in communities geographically distant from their traditional Country with a different history and different cultural practices. So, a 'one size fits all' approach to supporting Aboriginal people with disability and their families even within one geographic location, does not work.



This diagram shows the diversity of experiences of Our History and Our Ways for Aboriginal people with disability and family members.

3.3 Our Places

Our Places refers to the geographical location with which people identify. Identification is linked to the Aboriginal concept of Country relating to people's physical, cultural and spiritual birth-and-belonging-right which impact on social and emotional wellbeing. Not all Aboriginal people know about or identify with their Country and family. For example, some members of the Stolen Generation lost those links and may be re-establishing or forming new cultural relationships. Aboriginal people are diverse and it should not be assumed that all people have cultural knowledge and connection to place and family.

Our Places also refers to established gathering places - local, community-based Aboriginal-led organisations where Aboriginal people come together to meet or access a range of supports, cultural activities, and services. An organisation is considered to be Aboriginal-led if it:

- 👣 Is an independent, not-for-profit organisation, incorporated as an Aboriginal organisation;
- 👣 Initiated, controlled and operated by Aboriginal people;
- 👣 Is based in a local Aboriginal community, or communities;
- 👣 Is governed by an Aboriginal Board elected by members of the local Aboriginal community;
- 👣 Delivers services that build strength and empowerment in Aboriginal communities and people.

Some examples of Aboriginal-led organisations are: Aboriginal Community Controlled Health Services/Aboriginal Medical Services, Local Aboriginal Land Councils, Elders Groups, Aboriginal Corporations.



This image is adapted from the community map of the Baabayan Aboriginal Corporation in Mt Druitt. It shows that the Aboriginal-led organisation is a local gathering place for Aboriginal people from many different communities.

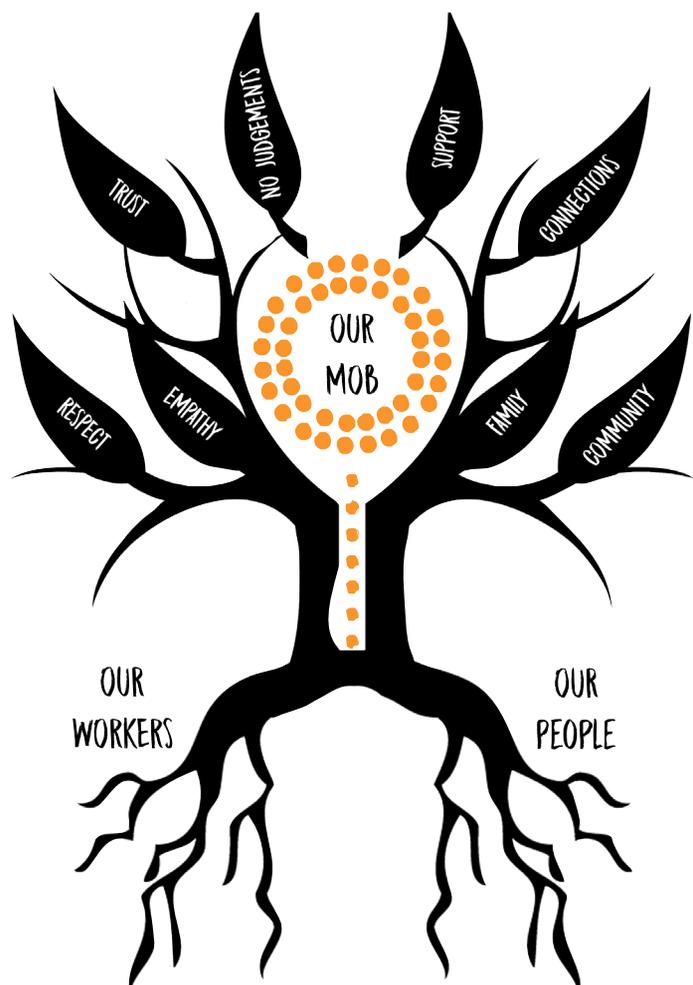
3.4 Our People

Our People encapsulates the diverse and intergenerational roles which Aboriginal people may hold within family and community. Roles are not mutually exclusive so that an Aboriginal Elder may also be a person with disability, a carer for a person with disability, and an advocate for others in the community who are older and/or disabled. Similarly, a parent of a child with disability may also be caring for an elderly relative with disability and may be a community advocate. An adult with a disability may also be a carer for an elderly relative and may have a role as a peer/mentor for a younger person with disability. Due to the strong bonds within Aboriginal families and communities, overlapping roles may be more prevalent than for non-Aboriginal people with disability and family members.

*“Care for carers!
We need respect, support and to be heard and listened to”*

Aboriginal women in particular fulfill multiple roles in the community such as family matriarch, leader, grandmother, mother, Auntie, Sister, kinship carer, community liaison officer, service provider and Aboriginal health worker. These strong Aboriginal women are often the main carers and reliable supporters and advocates for children, women and men with disability in families and communities. Carers need to be well supported to continue in their important roles including through provision of respite care for the person with disability.

It is important to understand the roles various people have as this will indicate who may be engaged in planning with the Aboriginal person with disability.



This image is adapted from the community map of the Durri Aboriginal Corporation Medical Service, Kempsey and Biripi Aboriginal Corporation Medical Centre, Taree. It represents the values and attributes that Our People and Our Workers bring to support Our Mob.

3.5 Our Workers



Our Workers refers to the paid employment of Aboriginal people to work with Aboriginal people with disability. A strength of employing Aboriginal workers is their existing cultural and local knowledge along with a perception that they may be less likely to be judgemental of Aboriginal people with disability and their family members.

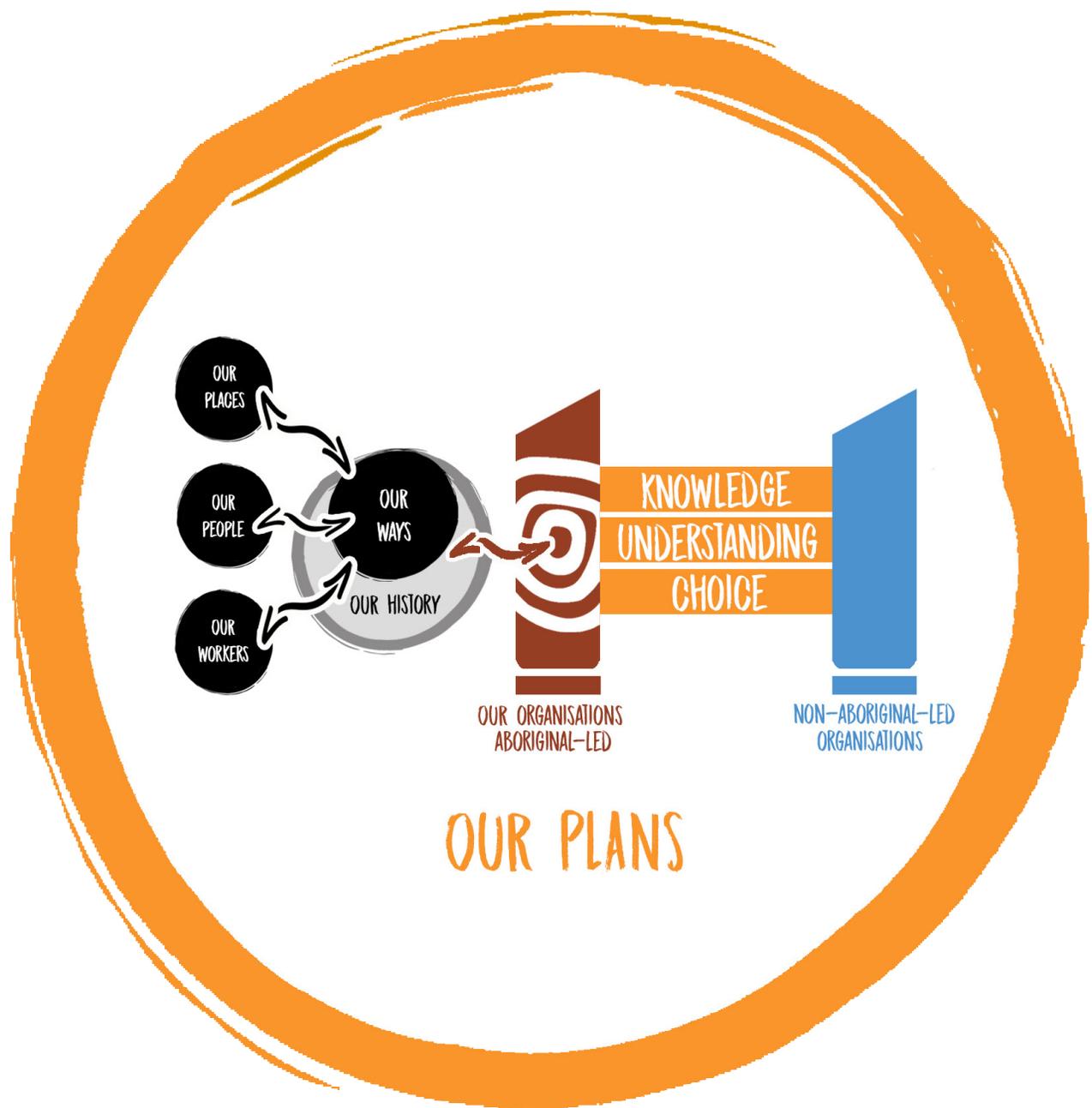
Some Aboriginal workers are employed by Aboriginal-led organisations, others are in Aboriginal-identified or generalist positions within non-Aboriginal-led organisations. Aboriginal-identified positions ensure representation of Aboriginal people in non-Aboriginal-led organisations; however, sometimes this results in the Aboriginal worker being regarded as the only person within the organisation who can work with Aboriginal people. When this happens, it is a lost opportunity for building all workers' capacity and understanding.

“We need more qualified Aboriginal support workers who are placed in jobs and then supported and trained up to do the job”

All workers require training and qualifications to work effectively across the spectrum of service users including with Aboriginal people. A diverse and culturally skilled workforce provides Aboriginal service users with choice regarding who they wish to have as a worker – an Aboriginal or non-Aboriginal person. Choice is important due to views about confidentiality. Some people will prefer to work with someone who doesn't know their family or past. Aboriginal and non-Aboriginal workers who have a disability or have been a carer for a person with a disability, also bring lived experience to the support they offer to service users.

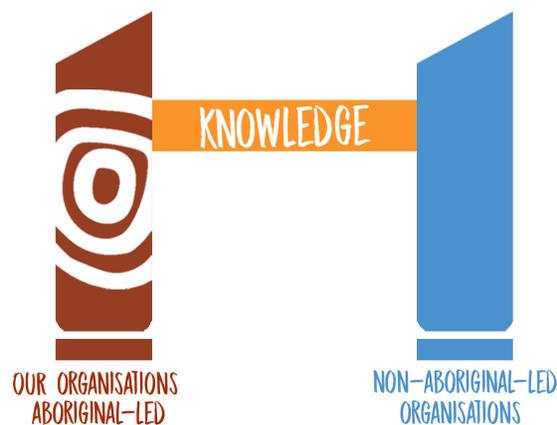
3.6 Three Bridges to Organisational Readiness for Planning

There are three bridges: *Knowledge*, *Understanding* and *Choice* which can help to bridge the divide between our Aboriginal-led and non-Aboriginal-led organisations in readiness for planning. The aim of the three bridges is to reduce waiting times and increase access for Aboriginal people with disability and family members to the full range of available supports and services through person-centred planning.



BRIDGE ONE: Knowledge through Information and Advocacy

Knowledge through information and advocacy underpins people's engagement in planning. People need access to information about the planning process and about the supports and services they might include in their plans. Some people with disability require the assistance of others to advocate on their behalf. Advocates may be other people with disability, family members, friends, or paid people.



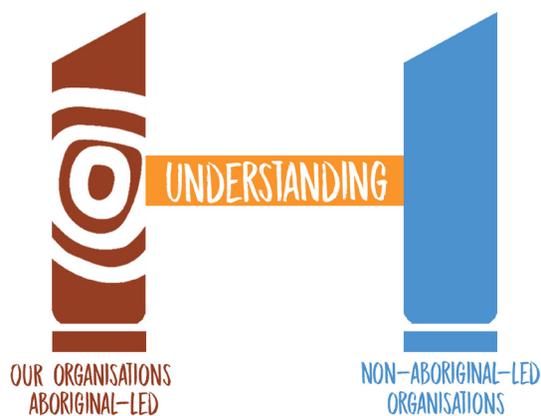
- Gaining and sharing knowledge about planning
- Providing accessible information and planning materials
- Hosting cultural events to discuss planning
- Building trust and support in order to plan
- Including counselling and advice in plans if needed
- Meeting and helping others to plan
- Sharing lived experiences about planning
- Learning culturally respectful ways to plan
- Developing accessible planning materials and processes
- Establishing partnerships with Aboriginal-led organisations to promote learning
- Delivering co-presentations on culturally-appropriate planning
- Practicing shared decision-making with Aboriginal-led organisations, drawing on shared knowledge to enhance planning expertise
- Developing planning policy that reflects lived reality
- Respecting and responding to lived experience of planning for Aboriginal people

Things your organisation can do to increase planning knowledge

- *Identify key person/s to talk with in Aboriginal and non-Aboriginal-led organisations*
- *Host cross organisation events in the local community*
- *Establish support groups for Aboriginal people with disability and family members*
- *Prepare Easy Read materials (e.g. Fact Sheets)*

BRIDGE TWO: Understanding through Cultural Respect, Awareness and Training

Knowledge alone is insufficient to bring about change. Aboriginal-led organisations, local Elders, Aboriginal people with disability and other community members, can build knowledge and understanding within non-Aboriginal-led organisations regarding what it means to be an Aboriginal person with a disability both locally and nationally.



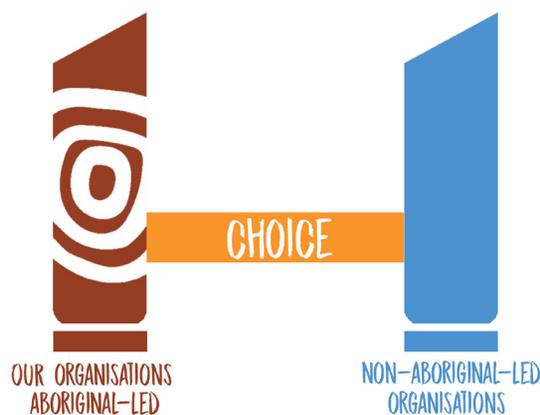
- Drawing on localised planning knowledge and trainers
- Including Elders and wise community members in planning conversations
- Planning always inclusive of Aboriginal people with disability and carers
- Developing localised planning training tailored to the community
- Learning about historical and ongoing impacts of colonisation; whiteness and power
- Developing awareness, competence, responsiveness, and transformational planning skills

Things your organisation can do to increase planning understanding

- *Find out about local Aboriginal-led organisations*
- *Learn about and respectfully acknowledge the past and the legacy of colonisation for Aboriginal people*
- *Engage Aboriginal Elders, community members, and people with disability and carers in cross-organisation planning discussions and training and provide financial and logistical support to make this happen*
- *Host a cross-sector networking event to build connections*

BRIDGE THREE: Choice Through Aboriginal-led Planning and Support

The ability to make choices about supports and services is underpinned by knowledge and understanding. Some Aboriginal people with disability and their carers may prefer to be supported by an Aboriginal worker who can contribute an inherent knowledge of Aboriginal culture and history which many people will find reassuring. Other people may prefer a non-Aboriginal worker. However, to work most effectively with an Aboriginal person with disability, non-Aboriginal workers will need to develop an understanding of the impact of colonisation. They will also need to learn, and practice, culturally respectful ways to work with Aboriginal people and communities. As indicated by the bridges both Aboriginal and non-Aboriginal workers will require appropriate qualifications and training that enables them to respond effectively to the needs of the people with whom they work.



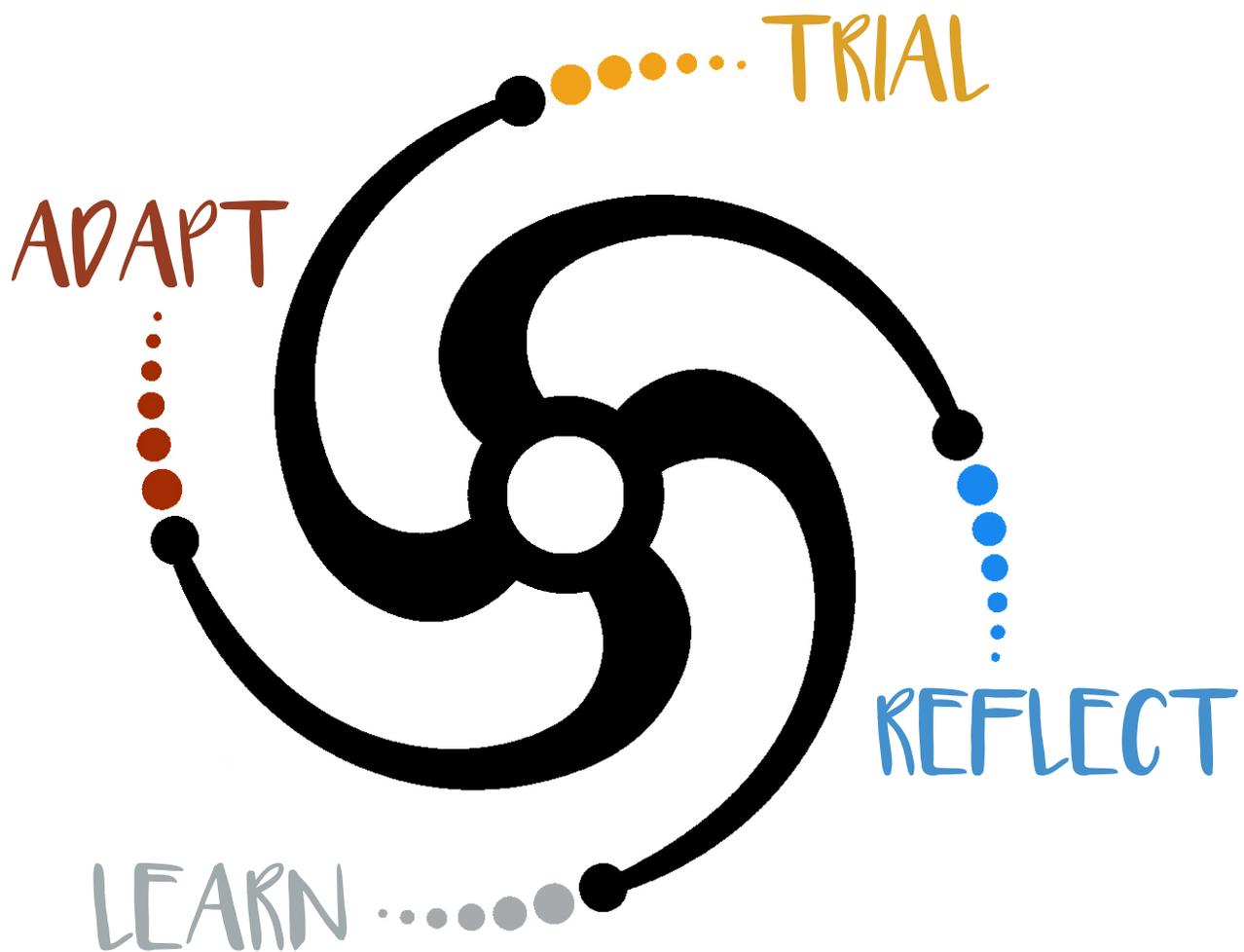
- Planning based on lived experience, knowledge and solutions
- Developing staff planning skills through qualifications and training
- Offering an Aboriginal planning workforce who people with a disability can trust
- Developing an understanding of impact of colonisations and the need for recovery our way
- Learning respectful ways to approach Aboriginal people with disability
- Providing the option of non-Aboriginal planners

Things your organisation can do to increase planning choice

- *Develop cross-sector partnerships to enhance planning choice*
- *Have written protocols detailing the terms of cross-sector partnerships to ensure sustainability*
- *Create shared planning strategies inclusive of Aboriginal people with disability and carers*
- *Keep in mind Aboriginal people with disability and carers preferred contact methods (e.g. text before phoning, wear shirts with logos)*
- *Facilitate personal independence and empowerment (e.g. need for transport to attend events and activities)*

3.7 Trial, Reflect, Learn, Adapt

The guide outlines ways for organisations to create locally-tailored pathways to planning with Aboriginal people with disability and family members involving both Aboriginal-led and non-Aboriginal-led organisations. Time and effort by all parties is required to make this approach work. Organisations are likely to try different approaches to engaging Aboriginal people with disability and family members in planning. Allowing time for reflection on what worked well and what could be done differently next time is part of the process of building organisational capacity to plan effectively with Aboriginal people with disability and family members.



TRIAL

- 👣 Planning with an Aboriginal person with disability may be a longer, more intensive process
- 👣 All people learn best through trial and error
- 👣 Support the person to try new things and encourage them to try again if it doesn't work the first time

REFLECT

- 👣 Encourage the Aboriginal person with disability and their family members to think and talk about what worked well and what they would do differently
- 👣 It may be hard for an Aboriginal person to do this as they may feel uncomfortable talking about when things went wrong

LEARN

- 👣 Remind the person that everyone learns best through trial and error
- 👣 Talk with the person about the practical skills they learned from their experience and how they might use those skills in other areas of their life
- 👣 Talk with the person about how they felt when they learned a new skill or did something different
- 👣 Encourage the person to recognise and celebrate their successes

ADAPT

- 👣 Build in regular opportunities to review the plan with the Aboriginal person with disability and their family members
- 👣 If you see (or the person/family tells you) that something is not working, make changes straight away before the person becomes discouraged
- 👣 Build on the person's successes to make future plans

SECTION FOUR:

Resources and References

Following are some recommended resources and references for organisations seeking more information about planning with Aboriginal people with disability. Some resources are Aboriginal-specific and others are not.



4.1 Useful Resources

First People's Disability Network

<http://fpdn.org.au/>



'Our Way Planning' - an individual planning tool designed for use with/by Aboriginal and Torres Strait Islander people with disability



'Living Life My Way'



Local peer support networks

UNSW Sydney Intellectual Disability Behaviour Support Program

<https://www.arts.unsw.edu.au/research/intellectual-disability-behaviour-support-program/support-planning/>



'Living the life I want: A guide to help with planning' - practical tool for use with/by people with cognitive disability and complex support needs.



'Being a planner with a person with disability and complex support needs: Planning resource kit' – a practical tool for use by practitioners engaged in planning with people with cognitive disability and complex support needs.

National Disability Insurance Scheme

<https://ndis.gov.au>

4.2 Planning in the National Disability Insurance Scheme

The National Disability Insurance Scheme (NDIS) is a significant change to the way disability supports and services are funded and delivered. Planning is central to the NDIS. The NDIS has three levels:

Level Three: Funded support packages

NDIS funding is provided to eligible individuals (rather than to organisations). To be eligible, a person must show they have permanent functional impairments resulting from their disability that significantly affect their life.

An eligible person must then develop goals relating to the things they would like to achieve and with a NDIS planner and/or Local Area Coordinator (LAC) it will be determined what supports and services they will need to achieve them. NDIS funded support packages can cover the lifetime costs of approved disability-related support and services that a person with disability needs to 'have a better life.' Funding may cover for example, personal carers, therapy, equipment, accommodation, and participation in the community.

Level Two: Information, Linkages and Capacity-Building

Information, Linkages and Capacity Building (ILC) focuses on community inclusion, providing support to people with disability (both those eligible for level three funding and those who are not) and the sector through access to information, and linkages and referrals to relevant supports and services. The ILC level aims to build the capacity of mainstream services to engage with people with disability and improve overall community awareness, inclusion and accessibility.

Level One: Insurance Safety Net

Level one focuses on social participation and creating general community awareness so that Australian society is inclusive of all people.

More detailed information about NDIS eligibility and processes can be found at: <https://www.ndis.gov.au/about-us/what-ndis> or by telephoning: 1800 800 110

4.3 References

- (1) Australian Bureau of Statistics. National Aboriginal and Torres Strait Islander Social Survey, 2014-15 Cat no. 4714.0 Social and Economic Wellbeing of Aboriginal and Torres Strait Islander people with disability. Canberra. <http://abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/4714.0~2014-15~Main%2Features~Key%20findings~1>
- (2) Baldry E, McCausland R, Dowse L & McEntyre, E. (2015) A predictable and preventable path: Aboriginal people with mental and cognitive disabilities in the criminal justice system. Mental Health Disorders and Cognitive Disability in the Criminal Justice System Project. https://www.mhdcd.unsw.edu.au/sites/www/mhdcd.unsw.edu.au/files/u18/pdf/a_predictable_and_preventable_path_2nov15.pdf
- (3) Biddle, N., Al-Yama, F., Gourley, M., Gray, M., Bray, J.R., Brady, B., Pham, L.A., Williams, E., & Montaigne, M. (2012). Indigenous Australians and the National Disability Insurance Scheme: The extent and nature of disability, measurement issues and service delivery models. Commonwealth of Australia: Canberra.
- (4) Collings, S., Dew, A., Gordon, T., Spencer, M., & Dowse, L. (2018). *Intersectional Disadvantage: Exploring Differences Between Aboriginal and Non-Aboriginal Parents with Intellectual Disability in the New South Wales Child Protection System*. Journal of Public Child Welfare, 12(2), 170-189. DOI:10.1080/15548732.2017.1379456.
- (5) Collings, S., Dew, A., Dowse, L. (2018). *Unpacking the complexity of planning with persons with cognitive disability and complex support needs*. Journal of Applied Research in Intellectual Disabilities, 31, 142-151. DOI:10.1111/jar.12381.
- (6) Collings, S., Dew, A., & Dowse, L. (2017). *They need to be able to have walked in our shoes: What people with intellectual disability say about National Disability Insurance Scheme planning*. Journal of Intellectual and Developmental Disability. Early online, 1-12. DOI:10.3109/13668250.2017.1287887.
- (7) Collings, S., Dew, A., & Dowse, L. (2016). *Support Planning for people with intellectual disability and complex support needs in the Australian National Disability Insurance Scheme*. Journal of Intellectual and Developmental Disability, 41(3), 272-276. DOI: 10.3109/13668250.2016.1151864.
- (8) Dew, A., Gilroy, J. & Lincoln, M. (2016). A sustainable rural and remote and Aboriginal and Torres Strait Islander workforce for disability. Research to Action Guide, Examples of Good Practice. Centre for Applied Disability Research. Available at www.cadr.org.au
- (9) First Peoples Disability Network (2016). Ten-point plan for the implementation of the NDIS in Aboriginal and Torres Strait Islander communities <http://fpdn.org.au/ten-point-plan-for-the-implementation-of-the-ndis-in-aboriginal-communities/>
- (10) First Peoples Disability Network. (2016). The Redfern Statement <http://nationalcongress.com.au/wpcontent/uploads/2016/10/The-Redfern-Statement-9-June-2016.pdf>
- (11) Gilroy, J., Dew, A., Lincoln, M., & Hines, M. (2016). Need for an Australian Indigenous disability workforce strategy: review of the literature. Disability & Rehabilitation, 38(25), 2491-2503. DOI:10.1080/09638288.2016.1201151.
- (12) National Disability Insurance Scheme (2017). Aboriginal and Torres Strait Islander Engagement Strategy. ndis.gov.au
- (13) New South Wales Government. (June-July, 2013). Living Life My Way: Yarnin' About Disability. Sharing what Aboriginal Communities across NSW told us. FACS: Sydney
- (14) NSW Law Reform Commission. (2012). People with cognitive and mental health impairments in the criminal justice system: Diversion. Report 135. ISSN 1030 0244. www.lawlink.nsw.gov.au/lrc
- (15) Ravindran, S., Brentnall, J., & Gilroy, J. (2017). *Conceptualising disability: A critical comparison between Indigenous people in Australia and New South Wales disability service agencies*. Australian Journal of Social Issues, 52, 367-387.

Developing This Guide: Researchers' Perspective

This guide was developed through a collaborative process involving 25 Aboriginal people from one remote, three rural and one metropolitan community in New South Wales working with researchers. We held community mapping workshops to find out about people's experience of planning. It would not have been possible to create this guide without the knowledge, expertise, advice and assistance of local Aboriginal people with disability, family members and staff from Aboriginal-led organisations.

We used six key approaches in developing this guide. These approaches may be useful for others working with Aboriginal communities:

Connecting and Collaborating:

From the very earliest stages and throughout a project, work collaboratively with Aboriginal communities to identify, plan, implement and disseminate the research.

- » In planning this research, we firstly undertook a consultation with one Aboriginal community to identify the need for the research and how it should be conducted. We asked community members questions like: *Do you think the proposed research will be worthwhile? How will the research benefit your community? Would people be interested in taking part? What research approach might work best?*
- » Once the project was funded, we established an Advisory Group made up of Aboriginal-led organisation representatives with expertise working with Aboriginal people with disability. This group provided advice to the research team on the approach taken, introduced and connected us with local Aboriginal organisations, and assisted in the development and dissemination of the guide.
- » We contacted each identified local Aboriginal-led organisation to work out how best to engage with members of their community. We were led by the organisation about the timing, venue and other logistics. We provided financial support to the organisation for local facilitator's time and for transport and catering.

Research Approach:

In thinking through the research approach there are key culturally and ethically important issues that must be considered:

- » We were advised that an active, and community-based, rather than individual, approach would work best and so decided to engage people in creating community maps to represent their experience of planning.
- » Community mapping is a fun and creative process, where people work together and use drawing, painting, writing and collage to create a map that represents their community. We chose community mapping because it is an informal, flexible, and inclusive way to learn about individual and community experiences.
- » We ensured we had ethics approval for the research from the appropriate institutions.

Aboriginal Led:

Make sure research is guided by Aboriginal people. Listen to and follow the advice of the Aboriginal community groups and organisations you are collaborating with. Have Aboriginal people on the research team.

- » Our research team included an Aboriginal researcher who had existing connections with a number of the communities. This person liaised with each local Aboriginal-led organisation to set up the workshop and recruit participants. Community members told us they felt more comfortable working with an Aboriginal researcher.
- » The non-Aboriginal researchers on the team learnt how to respectfully engage with Aboriginal community members.

Flexibility, Openness and Respect:

When undertaking research be flexible, open to criticism and feedback, and respect people's right to change their mind about taking part in the research.

- » We found that not all the people who came to the workshops wanted to contribute to the community maps. Some people preferred just to yarn with us. Some people decided to leave the research sessions when they got tired, or if they didn't want to make a map.

Acknowledge Time and Expertise:

Taking part in research is time consuming, and emotionally draining.

- » We recognised people's time and expertise by giving them a gift voucher and providing a catered lunch.

Bring Knowledge Back:

Once research is complete, return to the communities who participated and share the research results with them. Ask contributors for feedback and make changes accordingly.

- » We asked community members to review drafts of this guide to make sure their ideas and experiences were accurately represented. Copies of the final guide were then provided to the communities.

For more information and further resources visit:
arts.unsw.edu.au/idbs/resources