Centre for Mental Health
Melbourne School of Population and Global Health

Reducing stigma and discrimination towards people with mental illness

Phase 4: Consultations with Aboriginal and Torres Strait Islander people with lived experience

19 April 2021

Table of Contents

Executive summary

Background and aims

Reducing stigma and discrimination is critical to improving the wellbeing of people with lived experience of mental illness. Priority Area 6 of Australia's Fifth National Mental Health and Suicide Prevention Plan outlines the need for a nationally coordinated approach to reduce stigma and discrimination towards people with mental illness that is poorly understood in the community. In this phase of the project, we conducted consultations with Aboriginal and Torres Strait Islander people with lived experience, either their own or as a support person, or both.

Methods

We conducted online or in-person interviews and focus groups with 28 people with lived experience, either their own or as family members, friends and other support people. Most of the interviews were conducted face-to-face as requested by participants. All interviews were recorded, transcribed and analysed to identify key themes. The recommendations are based on the data collected as well as broader literature and input from the Aboriginal researchers involved in the consultations.

Key findings

Key themes included those relating to the importance of addressing the social determinants of Aboriginal and Torres Strait Islander health, including social disadvantage, racial discrimination and trauma (including intergenerational trauma).

In contrast, a number of participants raised themes relevant to the role of traditional knowledge, and connection to country and culture in social inclusion and healing. These themes point to the value of a strengths-based approach that acknowledges the importance of the cultural determinants of mental health.

Other themes related to the need for culturally competent mainstream mental health services and healthcare professionals, and their potential for more collaboration with Aboriginal Community-Controlled Health Services (ACCHSs). Furthermore, there is a need for community health education and anti-stigma campaigns driven by grass-roots organisations that incorporate culturally appropriate understandings of social and emotional wellbeing as well as some understanding of mainstream mental health and diagnostic frameworks to support early intervention.

Recommendations

Recommendation 12: Address stigma and discrimination towards Aboriginal and Torres Strait Islander people by:

- Ensuring that Aboriginal and Torres Strait Islander people have leadership roles in the Strategy;
- Ensuring that any actions taken under the national strategy:
    - are inclusive of Aboriginal and Torres Strait Islander peoples;
    - do no harm, and actively reduce underlying systemic disadvantage and inequality through addressing the social determinants of health;
    - take a trauma-informed approach that recognises intergenerational trauma and the trauma caused by colonisation and systemic racism;
    - take a strengths-based approach by protecting and promoting cultural determinants of health including traditional knowledge, family, culture and kinship by:
        - incorporating Aboriginal and Torres Strait Islander conceptions of social and emotional wellbeing;
        - drawing on family and kinship support structures, while ensuring there is greater access to support;
        - drawing on Aboriginal and Torres Strait Islander cultural strengths by taking an Inclusive holistic approach to healing;
        - emphasising the role of culture and connection to country in promoting good mental health (e.g. yarning, men's groups, arts and associated activities that enhance and utilise cultural connection and practices)
    - draw on previous successful Aboriginal and Torres Strait Islander health promotion campaigns;
- Ensuring access to culturally competent health services by:
    - addressing structural racism in health services (including harmful stereotypes about substance use);
    - implementing policies and procedures to ensure accountability for instances of racism, injustice, breaches of confidentiality and substandard care;

    - increasing participation of Aboriginal and Torres Strait Islander people at all levels in the mental health workforce (including healthcare professionals, Aboriginal Liaison Officers and peer workers);
    - ensuring health providers and social service providers receive training to improve cultural competence;
    - ensuring that culturally informed practices and methods are available in addition to clinical responses;
    - building on successes achieved in other areas of Aboriginal health, including in Aboriginal Community-Controlled Health Services (ACCHSs) which are underpinned by holistic perspectives of social and emotional wellbeing;
    - listening to, acknowledging and supporting the critical roles played by carers;
    - designing health services in collaboration with local communities to include outdoor spaces, Aboriginal art and to allow local cultural practices, including rituals or celebrations.
    - Scaling up evidence-based mental health education and carer psychoeducation programs tailored to and delivered by Aboriginal and Torres Strait Islander people.
- Implementing programs that educate non-Indigenous people about Aboriginal and Torres Strait Islander people's understandings of social and emotional wellbeing and healing;
- Implementing education and anti-stigma programs in Aboriginal and Torres Strait Islander communities that:
    - are led, co-designed and delivered by Aboriginal and Torres Strait Islander people from local communities;
    - build on the strengths of Aboriginal and Torres Strait Islander people in their culturally-based inclusivity and support for all family and community members (including those with symptoms, behaviours or diagnoses of mental illness);
    - focus on bridging Aboriginal and Torres Strait Islander and mainstream understandings of mental health to empower community members to intervene early when someone becomes distressed.

1. Background

Compared to the broader Australian population, much less is known about the experiences of stigma and discrimination in Aboriginal and Torres Strait Islander people with mental illness. The Fifth Plan is the first to specifically outline an agreed set of actions to address social and emotional wellbeing, mental illness and suicide amongst Aboriginal and Torres Strait Islander peoples as a priority. This is in recognition that Aboriginal and Torres Strait Islander peoples have higher rates of mental illness and suicide and rates of psychological distress more than twice those of the general population. [1-3]

1.1. Social determinants of Aboriginal and Torres Strait Islander mental health

Mental disorders arise as the result of a complex set of interactions between biological, psychological, family, peer, community, societal and cultural influences.[4] It is estimated that between one third and one half of the health gap between Aboriginal and Torres Strait Islander people and non-Indigenous people is attributable to differences in social determinants of health.[5] Therefore, improvements in mental health and wellbeing and reductions in stigma and discrimination require action to address the health inequities and inequalities that lie beyond the health sector. [6]

The mental health of Aboriginal and Torres Strait Islander people is directly impacted by cultural genocide and colonisation and the resulting disruptions in sources of social and emotional wellbeing in cultures, communities and families.[3] This has led to grief and loss; removal of children; economic and social disadvantage; family and community violence; incarceration; substance use; and physical health problems. Intergenerational trauma associated with these stressors adversely impacts mental health and contributes to stigma and discrimination.

Racism, both interpersonal and structural, compounds these mental health risks. In particular, racial stereotypes about substance use in Indigenous communities may contribute to and exacerbate the discrimination experienced by Aboriginal and Torres Strait islander people with mental illness. While links between mental illness and substance use are well established,[7] evidence shows that Aboriginal and Torres Strait Islander people are less likely to drink alcohol than non-Indigenous people, but when they do drink, they may be more likely to drink at dangerous levels.[8]

Any action taken to address stigma and discrimination in Indigenous communities must be underpinned by action to address the social determinants of health and an understanding of trauma, including intergenerational trauma.

1.2. Cultural determinants of Aboriginal and Torres Strait Islander mental health

Critically, any such action should also be underpinned by a strengths-based approach that acknowledges the importance of the cultural determinants of health.[9] This approach promotes cultural perspectives, including privileging Indigenous knowledge, protecting Indigenous intellectual property and traditional knowledge and preserving and promoting cultural integrity. Protecting and promoting traditional knowledge, family, culture and kinship can contribute to community cohesion and personal resilience. These factors are integral to healing and to the reduction of stigma and discrimination towards people with mental illness. Notably, they are often overlooked.

In order to ensure that a nationally coordinated stigma and discrimination reduction strategy is inclusive of Aboriginal and Torres Strait Islander people, particular attention should be paid towards Indigenous conceptions of mental health and wellbeing. For Aboriginal and Torres Strait Islander people, mental health is broadly conceived of as social and emotional wellbeing. This term carries a culturally distinct meaning as it connects Indigenous people to the health of their family, kin, community, and their connection to country, culture, spirituality, and ancestry.[10]

Notably, social and emotional wellbeing "is a deep-rooted, more collective and holistic concept of health and mental health than Western concepts. It also accommodates experiential differences: the disproportionate impact of poor physical health, lower income, unemployment, racism, lower educational attainment, poor and overcrowded housing and other social and cultural determinants on Aboriginal and Torres Strait Islander individuals, families, and communities when compared to the non-Indigenous population."[3]

The caregiving role is of great value to all people with mental illness, carers and the broader community. However, caregiving is often challenging and there is agreement that reform is needed to improve support for carers, including those in Aboriginal and Torres Strait Islander communities.[11]

1.3. Culturally appropriate mental health services

In the context of mental health system reform, a number of steps to closing the mental health gap for Aboriginal and Torres Strait Islander people have been proposed. Central to the reduction of stigma and discrimination is the expansion of culturally appropriate and accountable mental health services.[3] This involves expanding the mental health service capacities of Aboriginal Community Controlled Health Services (ACCHSs), ensuring that general population mental health services are culturally safe environments, and increasing the size and capacity of the Aboriginal and Torres Strait Islander mental health workforce, including in community-controlled/ community -based programs as well as mainstream government and major NGO services providing critical and in-patient care for Aboriginal and Torres Strait Islander consumers, including through community mental health services.

1.4. Leadership by Aboriginal and Torres Strait Islander people

Leadership by Aboriginal and Torres Strait Islander people, including health professionals and people with lived experience of mental illness, is central to ensuring that culturally informed practices and methods are available in addition to clinical responses. Addressing stigma and discrimination towards people with mental illness that is poorly understood in the community is likely to require a similar approach.

2. Project aims and rationale

2.1. Aims

This aim of this part of the project was to explore experiences of stigma and discrimination in Aboriginal or Torres Strait Islander people with lived experience of mental illness, either their own or as a support person.

3. Methods

This part of the project, interviews and focus groups with people with lived experience, was approved by the University of Melbourne Medicine and Dentistry Human Ethics Sub-Committee (application number 1955980.4), the Western Australian (WA) Aboriginal Health Ethics Committee (application number 1025) and the Aboriginal Health and Medical Research Council of New South Wales (NSW) (application number 1721/20).

3.1. Participants and recruitment

This part of the project involved interviews with Aboriginal or Torres Strait Islander people with lived experience of mental illness, either their own or as a support person. Our inclusion criteria were as follows: adults aged 18 years or over with a mental illness who identified as Aboriginal or Torres Strait Islander and who felt well enough to participate in an interview, or a carer of a person in this situation.

3.1.1. Recruitment

Recruitment and consultations were conducted by four Aboriginal researchers: Kate Kelleher (KK), Justin Noel (JN) who are based in NSW, and Isabelle Adams (IA) and Frank Proctor (FP) who are based in WA. They developed the recruitment process and liaised with local Aboriginal health and community services to conduct the interviews and focus groups. Participants were recruited through the following local community organisations: Yerin Eleanor Duncan Aboriginal Health Service (which is part of the Barang Regional Alliance on the NSW Central Coast) and Butucarbin Aboriginal Corporation, in Mount Druitt, NSW; and South West Aboriginal Medical Service (SWAMS) in Bunbury, WA. Recruitment and data collection took place in March and April 2021.

Each location used their preferred, locally appropriate recruitment procedures, informed by established respectful, culturally appropriate protocols that protected confidentiality. Participants were offered information about the study in a way that ensured that participation was entirely voluntary and informed by the knowledge that their choice about participation did not in any way affect their access to services.

3.1.2. Consultation Procedures

Participants were offered the option of having a support person accompany them during the interview or focus group. The interviews and focus groups took between 20-60 minutes, and were conducted in locations suitable to participants, with some conducted over the phone and some in person. Participants completed a consent form and a questionnaire asking for some basic demographic information. The interviews or discussions were generally unstructured, but included general introductions, background and questions relating to experiences and thoughts about mental health and services. Following the interviews, participants received a $50 voucher to reimburse them for their time and effort.

3.1.3. Safety protocol

Specific local arrangements were made to meet the individual participant's needs and preferences, including conducting interviews as focus groups, a range of direct referral options to local Aboriginal service providers and organisations, supported access approaches, reinforcement of locally-based programs and support options, and the more generic support options such as Lifeline, and Beyond Blue.

3.1.4. Data analysis

The interviews and focus groups were audio-recorded and transcribed by a professional transcription agency. Transcriptions were verbatim, but for the purpose of this report, some repetition was removed, and identifying information about names and places were removed.

Transcriptions were uploaded to NVivo, a software program that enables the organisation and coding of qualitative data. Data were analysed thematically. Two members of the research team (CM and JW) collaborated on initial coding of transcripts until a common approach was agreed upon. Key themes were then discussed with the principal researcher (NR) and Aboriginal researchers KK and JN to ensure that the data were interpreted appropriately.

4. Results

4.1. Sociodemographic characteristics or participants

In total, 28 people participated across three sites (see Table 1). The majority (71.4%) of participants were female, and over the age of 55 (67.9%), with a minority of participants below the age of 35 (3.6%). Among people with their own lived experiences, most reported living with bipolar disorder (38.5%) and other mental health conditions (61.5%). Most participants reported experience with being a support person (75%). Support people mostly reported providing support to people living with bipolar disorder (66.6%) or schizophrenia (66.6%).

Table 1. Sociodemographic characteristics of participants

	n	%
Gender		
Female	20	71.4
Male	8	28.6
Gender diverse (e.g. trans, gender fluid)	0	0
Lived experience*		
Person with their own lived experience	7	25.0
Support people	15	53.6
Person with their own lived experience and support person	6	21.4
Mental health experience (their own) [a]		
Bipolar disorder	5	38.5
Personality disorders	1	7.6
Psychosis	0	0
Schizophrenia	1	7.6
Other [b]	8	61.5
Do not identify with a diagnosis	1	7.6

Mental health experience (as support person) [a]		
Bipolar disorder	14	66.6
Personality disorders	8	38.1
Psychosis	10	47.6
Schizophrenia	14	66.6
Other [b]	2	9.5
Person does not identify with a diagnosis	1	4.8
State		
NSW	16	57.1
WA	12	42.9
Region [a]		
Metropolitan	10	35.7
Regional	19	67.9
Rural	0	0
Remote	0	0

[a] Total percentage >100% due to possibility of multiple responses. [b] includes depressive disorders, complex PTSD and other trauma-related conditions, and psychotic experiences other than schizophrenia

4.2. Themes

A number of key themes emerging from the consultations overlapped with those from consultations with non-Aboriginal people with lived experience. In this report, we focus mainly on findings and additional recommendations that are unique to Aboriginal and Torres Strait Islander people.

In many cases, these issues identified in the earlier phases of the project were even more prominent for Aboriginal and Torres Strait Islander people. These include limited access to services, lengthy times to diagnosis, substandard care, and issues arising from structural discrimination relating to a power imbalance between health professionals and people with lived experience. Carers also spoke about inadequate support and lack of recognition of their critical role in supporting people with long-term mental health conditions. This included repeated incidents of medication changes, inadvertent overdosing whilst in hospital care, and a consistent lack of provision of education and information on underlying diagnosed conditions by mainstream health and mental health service providers. Aboriginal leadership of services and activities targeted to Aboriginal communities, involvement in co-design and delivery, and listening to people were seen as critical, as noted in the earlier phases of the report.

Thus, the overall recommendations apply equally to Aboriginal and Torres Strait Islander people and care must be taken to ensure that any action taken under a nationally coordinated strategy actively reduces existing health inequalities.

A number of participants talked about Aboriginal and Torres Strait Islander culture as a source of strength due to its ability to promote resilience, inclusion, and healing. While some services (principally ACCHSs) may have incorporated culturally appropriate elements, there is a need to harness these strengths on a much larger scale. Incorporation of a strengths-based approach that emphasises the centrality of culture in the health of Aboriginal and Torres Strait Islander people may also be seen as a key aspect of a national strategy. The main themes and subthemes are listed below in Table 2.

Table 2. Themes emerging from the data

Main theme	Subtheme
Social determinants of health	Trauma, including intergenerational trauma
	Racial discrimination
	Housing
Cultural determinants of health	Social inclusion
	The role of community advocates
	The need for more support for carers
	Connection to country and culture in healing
Community education and anti-stigma programs	Culturally appropriate understanding of mental health
	Approaches to delivery of interventions
The need for culturally competent mental health services	Positive experiences in Aboriginal Community-controlled health services (ACCHSs)
	Racial discrimination in mainstream health services
	Lack of cultural competency in health services
	Negative impact of seclusion and restraint
	Concerns about privacy and confidentiality
	Aboriginal staff in mainstream mental health services

4.2.1. Social determinants of health

Many participants referred to a holistic concept of individual and community wellbeing, and many comments reflected the impact of the social determinants of health. All participants highlighted the adverse events they and their community had experienced throughout their lives and how these had impacted on their mental and physical health. Participants spoke about experiences of injustice including those that contributed to the onset of their mental illness. Topics included grief and loss, discrimination, inequality, erasure of culture, unsafe social housing, racism, unjust incarceration and racial violence.

(1) Trauma, including intergenerational trauma

Several instances of trauma (including intergenerational trauma) compounded by social disadvantage were highlighted by participants, although not all participants were from socially disadvantaged backgrounds These experiences (past and ongoing) not only contributed to poor mental health today, but also to a negative spiral of more social inequalities, reduced access to services and support, which then pose further risks to mental health. In some cases, participants talked about the trauma not being recognised, not being believed or not being taken into account in their interactions, including those with health services.

> *P1: So you're going to have people like me, we're the ones that's been affected by the stolen generation, growing up on a mission, I said you're going to see that from us, and the trauma, yeah ….. there's no categories on there, we're just all unwell yeah. But that cultural identity needs to be put back. (Consumer)*

> *P10: Oh from 1982, 20 years, no in 40 years I've lost 11 people. Grandchildren, my own child, my husband and one great grandchild and I've lost my sister and brother ….. because it brings up from when I was younger, and dad was incarcerated and then we were taking from our mother and it just keeps going. I don't talk much about it, I don't know why, because it upsets me. (Consumer and support person)*
>
> *P1: [summarising many premature deaths in the family] So I was wondering why I was in this bad headspace, I couldn't identify what was wrong and then I just kept losing my stuff and cracking up and all sorts of stuff. And then eventually the doctors decided that they'd diagnose me with a mental health illness, post-traumatic stress disorder, complex it is, and bipolar, but one doctor thinks the traumatic, post-traumatic stress disorder, but I have incredible anxiety attacks and panic attacks, so it's a combination of everything. (Consumer)*
>
> *P6: So it was a traumatic event that sent her on this journey, you know. But she wouldn't talk about the event. You know she didn't want to tell me about what happened, so – like she's locked it away, she's not going to tell anybody you know. (Support person)*

(2) Racial discrimination

A number of participants described experiences of racial discrimination from the general community and social services (racism in health services is included in section 4.2.3).

> *Facilitator (F): And that call [to the police], would that have come from an Aboriginal person or a non-Aboriginal person?*
> *P1: Non-Aboriginal person you know. Blackfella wouldn't ring you up, they wouldn't ring the coppers on you, there's no way, a blackfella would come and have a sticky beak to find out what's going on*
> *F:So if I've got it right it sounds like there's a lot of discrimination against people in that attitude, that lateral violence stuff from community, and a lot of the services as well*
> *P1: Yes absolutely (Consumer)*

Some participants talked about negative experiences including stigma and racism of other services including police, Centrelink, the Housing department; and the need for trauma informed care.

> *P1: Centrelink is the worst. At least like – because Centrelink and [specific mental health service][] I'm talking about mental health in [location] LGA and I'm talking about [specific]mental [another specific]health service, they're both equal. Like they're the worst – you know what, they are worse than the mission managers that I experienced as a kid on the missions. They're worse. (Consumer)*
>
> *P3: Alright from a place perspective working at [Regional police station] for 30 years, [they think] all blackfellas are mental. Alright, all black fellas have got mental health issues. They're all junkies and they, just the attitude of some of the coppers down there is just unbelievable.* (Consumer and support person)
>
> *P15: And what had happened was the house caught fire one night, and...the house burnt down, the old man was okay, [she] was asleep in the park and the police just decided that she lit the fire. I know, she was the only Aboriginal person in the park so we'll just take her. But yeah she was remand but was there for 3 years. (Support person)*
>
> *P14: Well I think post-traumatic stress isn't really understood because of the triggers and like just how bad it can get like I can turn into a basket case, and I've had to deal with police as well and they think I'm on drugs but I'm having anxiety attack after anxiety attack and I'm so overwhelmed. (Consumer)*

A number of participants spoke about being impacted by stereotypes of Aboriginal people being seen as heavy users of drugs and alcohol, resulting in higher levels of stigma and resulting lack of attention to physical and mental health conditions.

(3) Housing

Lack of access to adequate housing was mentioned by several participants and is an issue of particular importance, given the high rates of substandard social housing in many Aboriginal communities.

> *P14: So like if you were hoping to get sane this probably isn't the place you'd choose because there's just constant slamming of doors, people threatening each other, violence, abuse, assaults... And if I was mentally well enough and still had a job I'd be renting privately, and it would be where I want to be, so it all hinges on if I was well enough I wouldn't have to be here. (Consumer)*

> *P3: My nephew, well it's hard to get a house, because they won't house you. I've just lost a nephew the day after Christmas, couple of days after Christmas, severe mental health, he, myself, his mother, the housing officer, we tried and tried and tried to get him out of these units, because it was a haven, druggies everywhere. And just, we wanted to get him in with the pensioners, old fellas, but because he had a drug issue, can't put him there, and I said well if we put him there, he's a caring kid, if you don't know him on the other side of the drugs he would do your gardening, he would look, he'd go down the shops with them old fellas. But you know that poor kid was left in that flat to be bashed by his fucking woman, and died, 2 days after Boxing Day. (Consumer and support person)*

4.2.2. Cultural determinants of health

As noted above, any action to reduce stigma and discrimination should be underpinned by a strengths-based approach that acknowledges the importance of the cultural determinants of health.[9] A number of participants raised themes relevant to the role of traditional knowledge and culture in social inclusion and healing.

(1) Social inclusion

Several participants highlighted the critical role of kin in recognising mental health problems in family and friends and providing ongoing support. This support was provided in three main ways: (1) recognising a problem when people experiencing symptoms of mental illness were often unaware, (2) initiating and advocating for the person in health or welfare services, and (3) providing ongoing support in services and in cultural experiences of healing (e.g., fire drums, going on country, yarning).

Many participants highlighted the strength of the Aboriginal community's response to members of their community experiencing mental health problems, citing the important role that Aboriginal people, kin and community played in people's lives. Acceptance and support from community members and tolerance for difference (sometimes indicated by the term 'Gwange' in some communities or 'nurragar', 'womba' or 'silly' in others, non-derogatory words used to refer to a person who acts differently to the norm) and empathy were seen as cultural strengths that can play a role in tackling stigma. Participants described situations in which they or other members of their community looked out for kin known to be experiencing mental health problems through prioritizing their safety by keeping them at home and making sure their needs were being met (e.g., food, safe housing), helping out where they could (e.g., offering money or food to people experiencing homelessness, informally checking in with the person or their family), prioritizing a person's story as part of their understanding of them and being accepting of differences, and providing advocacy and gatekeeping (e.g., intervening on behalf of loved ones in services to make sure their needs and rights are being met, recommending and helping people access appropriate services). Participants described situations in which Aboriginal and non-Aboriginal community members responses to homelessness and people with mental health issues differ, with Aboriginal people knowing each person has a story, expressing greater empathy and a willingness to help and look out for people.

> *P6: Well Aboriginal community and people do accept, whether you're black, white or whatever, they accept people and if you're drunko, they accept you know, you know, if you take drugs well hey, we look after each other you know in the community setting. But if you're not in the community, you're out there, in the broader community, it's a bit hard I think for that person. (Support person)*

Further, some noted that these positive community behaviours towards peoples with experiences of severe mental illness highlighted a key difference and strength of the Aboriginal people compared to non-Aboriginal people.

> *B9: I think because we're accepting and we probably more than likely have someone like that in our own family, in more families. And I think from a spiritual perspective too, yeah, I absolutely think from a spiritual perspective in my rationale of everything that I've experienced, some of how he sees the world isn't a bad thing. You know what I mean? Like how he might hear certain things or if he's got voices or if he's seeing things, or his psychosis. I think I'm interested in that, Mum's interested in that, oh what did you see or how did that – and art and things like that, I just think that we're more accepting as people, than non-Aboriginal people (Support person)*

> *P15: Our mob are more accepting of you know, like everything, difference, whether you're gay, whether you're putting on a dress in the community at the camp, it's just wonderful. Our people, sometimes you know like the older ones mightn't understand what's going on, or sometimes you know you hear this oh you know he's got the devil in him you know, or I've had an incident up in the Torres Strait Islands where they said oh no*

> *no he's no good boy, he got devil. And then you've got to try and say to them well you know no he hasn't got devil in him, because that devil thing could be really detrimental to that person.* (Support person)

Support people described receiving support from fellow community members.

> *P6: Yeah family can help as well, like my family was real accommodating, and I explained the situation with my daughter, because if you don't explain then they don't need to be scared, you know, if you don't explain they're going to be afraid, and they won't have anything to do with the person. So it's best first off to let them know what's happening, what's wrong with the person, but say they are on medication and all you've got to do is just be there for them. Make them a cup of tea, give them some lunch. Yeah that's it, they're just normal like us but just different. (Support person)*

> *P2: Hey aunty, you need to know your boy, he knew my son, and he said he needs someone to help him, and I know about this program, and he told me about I think it was the beginning of NDIS where he said you can get people to pay to come to your home and take them out, he needs to go out, he needs to be in the park, he was telling me all my son's needs. How good is that (Support person)*

(2) The role of community advocates

A few support people detailed stories of members of their community falling through the cracks and not receiving any welfare or health services, sometimes for decades, until a member of their community took them under their wing. Several support persons highlighted that they had been involved in the care of their loved ones for many decades and without their involvement imagined the outcomes of their loved ones would have been poor. Several describing how their kin relied heavily on their ability to advocate on their behalf, spending a lot of their time with organising and coordinating with social and health services (e.g., NDIS) on their behalf.

> *P9: For example if [Brother's name] didn't turn up for a meeting, his parole, he will automatically assume, and I say if you've got a problem you just text me and email me, because I want it all in writing and what you think, oh yeah I think [name] is on drugs again, because he didn't turn up to a meeting. I rang [Brother's name], [asks] what's wrong, he goes I'm a the dentist, I'm getting an abscess out, oh hello yeah no he's at the dentist, he's at the AMS. There's things like that all the time. (Support person)*

For example, one support person detailed the long journey to support someone with undiagnosed severe mental illness to receive basic social services and culturally appropriate healthcare that they had never received even though mainstream services had been supporting her for years.

> *P15: And then we met, and we became friends, and I recognised that there was something wrong, something wrong or somebody that may just need you know a sister to help you know. And that's how we became friends. And we started, our friendship started with a fire, because I had a fire drum made out of a washing machine, and I sort of recognised that something, we just needed to do something like that. Because it wasn't like hey come over for a cup of tea, or all of that sort of stuff. And that's how we started talking and I recognised that there were a lot of issues, and it took a while for me to encourage her to even hook into the medical centre. And then we finally did that and yeah she was diagnosed with psychosis, schizophrenia. (Support person)*

> *P15: She was incarcerated for 3 years without any charge. And was found by a social worker who then got her out of there and she had nowhere to go except back with her friend.... And until we hooked into the Aboriginal Torres Strait Islander community health service, she would've probably hidden behind those doors and not answered the door to the mainstream service providers that were supporting her... we went from them at that stage getting her better, where she needed to have her own home, she'd never had a home, her own place. She's lived in a park or lived with people or lived with family. So that's when her and I started the journey of getting all her paperwork, because she didn't have a birth certificate, she didn't have anything, no ID, nothing like that. So we went and got all of the stuff, and then we applied at the Department of Housing.(Support person)*

Several participants highlighted either that they or the person they were supporting were previously unaware of their condition which impacted their quality of life and delayed treatment. Participants journeys with treatment were often initiated by family, friends, or people in services.

> *P13: The woman the Aboriginal officer at the court asked me if I wanted help because she came to see me and asked me questions and she put me onto [Counsellor] and [Counsellor] rang me. (Consumer)*
>
> *P12: Right the Aboriginal people as they come up to me and identify as Aboriginal I would help them and guide them in the right direction where to actually go for the support and out in the community I would do the same thing by helping them and leading them into talking to your GP or a counsellor or going to the community centre or the outreach*

Participants described their own or the community's experience of not understanding or being able to recognise mental health problems and know where to get help.

> *P2: Then at 14 he started to hear a lot of voices, but he didn't tell us, so he went and decided to try and get rid of the voices himself with marijuana. Then it really didn't, we didn't get any support or anything with it, because we didn't know what we had and what we were dealing with. (Support person)*

However, support people with previous education of mental health or knowledge of the system through work highlighted how these experiences played a critical role in helping those they were supporting.

> *P6: It's hard for them [Aboriginal families] to understand what's happening to that child, or adult. Because you'd have mental illness any time in your life, and because I went to university I've studied mental illness, so I know all the little signs and things like that, so I kept a really good eye on her, because I knew all the symptoms and what would happen, and medical situations. (Support person)*
>
> *P2: His deepness of this psychotic – police picked up, police taking him – that was another big thing to have to get my head around was the police were – I took a long time in letting go of understanding the safety for everybody in terms of his care. Like no one prepared me for it, I wasn't prepared, who is? But then I noticed there was no referral either, given to me, to look for that support. So if you had a good staff person, if you had a good nurse.(Support person)*

One participant highlighted that the Aboriginal community has largely looked after people with mental illness in the community without any assistance from the mainstream system in providing mental health support.

> *P2: I think our elderly, older members of community have a greater resilience could I say, they're resilient to mental health because we've gone a long way without the system, and a lot of – when I hear some of the families talk about their family and who they're looking after, they're looking after people before and out of the system. Some of them haven't even been identified as mental health, they're not under a mental health system. They're being looked after at home. (Support person)*

(3) The need for more support for carers

While the caregiving role is of great value to people with mental illness, carers and the broader community, it is often challenging and there is agreement that reform is needed to improve support for carers. This was reflected in participant comments. While navigating initial onset of symptoms or episodes that required immediate assistance from police or health services, some participants mentioned that support people were often left out of receiving additional care, understanding and support for managing these difficult and distressing situations.

> *P16: I didn't have any support, we had to do it as a family. And I had a couple of good friends. So the first few years was horrific. (Support person)*

One support person also highlighted that responsibility was placed on them to manage their loved one's periods of poor mental health. This responsibility was placed on them either by mainstream services themselves due to lack of services, or as a result of avoiding mainstream services. Participants detailed avoidance of mainstream services due to previous experiences of racism, culturally incompetent services and instances of substandard care and breaches of confidentiality (see section 4.2.4).

> *P7-8: I said well why can't somebody go around, why can't you send, oh we can't get out there 'til next week. But here she is she's having suicidal thoughts, she's in pain, I said well why can't someone go out and see her now, oh we can't get out there 'til next week (Consumer and/or support people)*

Some participants highlighted that support people needed increased support and recognition of their vital role.

> *P17: The positive side is we acknowledge that there is an issue or a problem or a disorder, but it's the how we work towards dealing with it, people, the family members or the support people are worn out, so there needs to be something put in place in order to, for them to go. (Consumer and support person)*

> *P20: [suggestion to have] Families, or have ones along the family line who can get paid to carry through, who know the family, who can have the yarn. But they're getting paid for going to sit, give the family a break, or taking them fishing or hunting, whatever. (Support person)*

While participants noted a few situations in which police provided effective support, these situations often involved police officers that had a working relationship with the support person, knew of the person's situation and how to manage their needs, or had received training in managing crisis situations effectively.

One support person who worked in police services highlighted how responsibility was placed on them to manage crisis situations involving Aboriginal and Torres Strait Islander people despite not having the appropriate training or safety measures to do so.

> *P3: One job we went to where a girl was psychotic, you seen that thing on the news the other night that one with the brick up at the [place] – me and my work partner did that, we were reversing, and that girl was running at us with a brick. And I said we need that sort of training too, just like you coppers, youse have got a vest on, youse have got a bloody gun on your hip, what's the little blackfella got. Here cop this brick. So yeah we all deal with it differently. (Consumer and support person)*

(4) Connection to country and culture in healing

Several participants mentioned the importance of arts and associated activities, yarning, activities outside and connection to country as playing a critical role in healing and recovery. Such activities should be promoted as part of a stigma reduction strategy.

> *P5: Maybe while they're in there, to get them to do something constructive, like my wife likes to sew, and she wasn't allowed to take knitting needles in there. I suppose you could understand why yeah, but she liked to crochet you know, just to have, like if they're going to be in there for a length of time, have some sort of program to get their mind occupied, instead of just waiting for their next pill to take.* (Consumer and support person)

> *P15: Well my experience from traditional people up north, that's why we decided on the fire drum and we just used to sit there, and we had – yeah it was amazing how much it helped her.* (Support person)

> *P1: You know our foods, everything. Like I go to the elders group every Tuesday... and they used to have this place deliver catering all the time, and oh God it was shocking tucker, oh dear, it was wicked you know. And I said to them, sister why are we getting white fella's tucker to come down here, these are all black women here, we all grew up on a mission, we need mission tucker you know.* (Consumer)

> *P5: Yeah, well like I had a mental health problem, and it was only because I was sitting at home not doing anything. Now …. we meet here every Wednesday, we do a bit of painting. It can't hurt someone with the painting. You know, and it's a little men's group we've got going, and it has helped me immensely.* (Consumer and support person)

> *P16: But you know my son was lucky, his culture looked after him, and whether people – some people mightn't believe it, but our culture is a very strong culture, and he's always been very strong in his culture. In fact he used to do repatriations and he used to play the didge and all those sort of things. He was always very involved. (Support person)*

> *P24-28: And we survive. But at the same time we still have a good time, a good yarn stories, you know that's the best medicine. (Consumer and/or support person)*

4.2.3. Community education and anti-stigma programs

Many participants noted the need for education to improve mental health literacy, advocacy, and reduce stigma in ways that were culturally appropriate and that could be accepted by the Aboriginal community. However, views about how to discuss mental illness in Indigenous communities differed between participants. Some preferring conceptualisations that were more culturally relevant and easily understood by the Aboriginal community, while others supported the benefits of using diagnostic terminology in programs and activities to promote greater understanding within the community, provided these terms were explained in meaningful ways.

> *P17: Education is a big part because that's a powerful weapon used, if someone has the knowledge to be able to use that information, maybe we may be able to save or improve the quality of these people's lives who have these issues.(Consumer and support person)*

Several participants highlighted that their communities had their own ways of describing and talking about mental health, and that using their own language to talk about mental health was a means of improving community understanding. Several participants spoke about the need for yarning within their communities as a way to facilitate conversations about mental health and decrease stigma. Specifically, one participant described the need for grass-roots initiatives in which Aboriginal people could talk about mental health in their own language.

> *P1: We need to have our own space, we need to have our own place where women and men can get together and talk about mental health and go through some healing and that together. I'm an educated woman but I don't know how to comply to white man's ways of mental health. That's something that they've just given me, and I've got to learn about that. I don't know how to learn about that, I don't know what that is. But if it was the black fella's way and they're telling me, I know what they're talking about. But we don't have any black fellas to sit around and talk and yarn. It don't have to be an educated black person, it can be just an elder or someone like that, another woman, sitting around talking about stuff and just doing the healing camp or something you know. Like look at all this ground here, we can stick up a tent and go out there you know. (Consumer)*
>
> *P20: And people that don't have an understanding or haven't come up against this illness, what it is about and what's going on, and just the attitudes, lot of negative, a bit of positive for the ones that do know or are going through it. But the negative you know there's bad things said about them, and don't want to go there because so and so. You know because they don't understand, they don't know how to handle it and manage it, and they feel uncomfortable a lot of people, or different ones.(Support person)*

Education programs to boost the capacity to support people with either emerging or long-term mental illness were also seen as having a role. While it was highlighted Aboriginal community was accepting of differences in people with severe mental illness, improving community responses to recognise when difference indicates distress, and how to intervene was highlighted as needed. A few support people mentioned that substance use impeded their or other people's ability to recognise underlying mental health problems and that substance use and mental health were intertwined.

Mental Health First Aid training was seen as useful in improving people's ability to recognise and intervene early while more intensive psychoeducation, particularly around issues such as post in-patient support and medication was seen as important for carers.

> *P15: Totally, I reckon everyone should do the mental health first aid just like first aid and CPR. Because everyone would be so much more in tune with people around who's got bipolar, schizophrenia, and all of that. And you know it's, yeah I just, people would look at people differently as well. Because the thing is you know, if someone is having an episode in a shopping centre, and if you have that, or half a dozen people have got that mental health first aid, you know it's amazing it can quell a lot of angst and stuff, because people get frightened you know, and people, it's like I was explaining it to that... boy, and people were getting frightened, but it was really good because the police sat down, everyone calmed down. (Support person)*
>
> *P16: [Mental Health] First aid for Aboriginal people, and mainstream people can do it also, and that's very important, because if people are going to be working with Aboriginal people they need to know the signs. Like with my son I knew the signs, I knew when he was unwell, by just some of the things he would say to me, and I'd know straight away he hadn't been taking his meds, and that's why when we had a meeting, and he was there too, never had a meeting without him being there. (Support person)*

(1) Culturally appropriate understanding of mental health

Participants had mixed responses to Western conceptualisations of mental illness and their appropriateness. Some participants were receptive to using mainstream language for describing mental illness and specific diagnostic experiences, particularly with regards to their acting as a gateway for increased self-understanding and accessing effective treatment for the person. However, several participants perceived the term mental illness and diagnostic labels to be stigmatising, leading to discrimination by family members and the wider community, feelings of being misunderstood, exposed and hurt, and decreased help-seeking. Specifically, one person described how people who engaged with an Aboriginal medial service (AMS) had previously avoided organisations that used mental illness terms.

> *P21: A lot of the people that come to us, I mean before [AMS], would use the terms mental illness and then straight away you'd back away. You wouldn't want to be part of it, because it was still an area that was very hard to specifically talk to Noongars with. (Support person)*

Some participants said that Western conceptualisations were inappropriate terminology to describe their experiences. One participant noted that the separation of mental and physical health, or diagnostic labels did not make sense to them due to the need for physical and mental health to be treated holistically. Several participants said they were unfamiliar with terms commonly used by health practitioners, which caused confusion and misunderstanding and noted that some practitioners were unfamiliar with Aboriginal and Torres Strait Islander people's ways of talking. Some participants noted that diagnostic labels did not make sense to them, or did not take into account their circumstances and experiences as a whole person. Further, several participants highlighted that Aboriginal people and communities had their own ways of describing experiences related to severe mental illness. One participant described using the word "spirit" to describe a person's mental health experience, another participant described how their father used Noongar language to describe severe mental health conditions, and two other participants spoke of inclusive and non-stigmatising coverage terms their communities used to describe experiences related to severe mental illness.

> *P17: When I talk, I talk about our spirit, when our spirit weak, make our mind weak, and when our mind takes over, so that everyday language needs to come into even more, so you've got a strong mind you've got a strong spirit, or you've got a strong spirit you've got a strong mind. (Consumer and support person)*

> *P1: Because we don't see it the same way as white man. Our mental health is caused by all these things, and then what the white fellas do they separate them all and then start categorising, you know post-traumatic stress disorder, personality disorder, bipolar, but we just look at that and think oh this is what the white fella's done to us because we're living on a mission you know... everybody becomes unwell you know, whether it be their diabetes playing up or whatever,... unwell. Because it's part of that trauma that we've been fucked over you know. (Consumer)*

> *P1: I'm an educated woman but I don't know how to comply to white man's ways of mental health. That's something that they've just given me, and I've got to learn about that. I don't know how to learn about that, I don't know what that is. But if it was the blackfella's way and they're telling me, I know what they're talking about. But we don't have any black fellas to sit around and talk and yarn. (Consumer)*

(2) Approaches to delivery of interventions

Participants described that understandings of mental illness might be better received when disseminated through members of their own community and tailored to local languages. Some had preference for face-to-face contact through grass-roots approaches involving elders or yarning groups and barbecues, to build trust before receiving information. Others thought messages could be spread through the broader community via written means (posters) or media (local radio or mainstream tv advertising during footy matches) delivering key messages or narratives that promote understanding of how to recognise symptoms and find support, decrease uncertainty, fear and stigma and increase help-seeking. Some participants noted that while messages around COVID-19 related hand hygiene, and safe sex practices were commonly seen, messages around mental health were lacking.

Further, a few participants discussed the importance of considering gender as part of the approach, in which discussions of mental illness could be targeted to women's or men's groups.

A few participants highlighted that there was a gap in mental health awareness in community and services, with some participants mentioning that there were no anti-stigma strategies or messages being promoted in their community.

> *P24-28: To be honest I reckon there's not enough said in regards to this mental illness or mental health, not unless you've experienced and you're sort of getting help. But I think the message should be happening b efore it gets to that stage (Consumer and/or support people)*

A few participants recommended Aboriginal medical services could be more involved in providing information through pamphlets and posters, or by coordinating community events.

> *P6: Yeah like be great you know when we have a NAIDOC day or festival or something, have a stall with all this info how you can help people you know. (Support people)*

> *P22: For the people from the [name] AMS to put together functions to learn more about these things. (Support person)*

4.2.4. The need for culturally competent mental health services

The need for culturally appropriate health services was highlighted by most participants. Many said they were unfamiliar with terms commonly used by health practitioners, which caused confusion and misunderstanding. Several participants said the 'whitefella' way of doing things, including reliance on medication, exclusion of family members or support people in discussions or decision making, and keeping people in small rooms, did not work well for them, and they needed culturally appropriate ways to heal. A lack of culturally appropriate support in terms of information and healthcare practitioners was mentioned by several participants. Others noted the lack of Aboriginal and Torres Strait Islander healthcare staff and the need to build capacity in this area.

> *P1: But the horizontal violence was just so, still raw and rampant today, you know the oppression, the stigma, discrimination, everything, it's still right there. But not having any access to mental health services back then, is the same today. It hasn't changed. There's no proper mental health facilities access for Aboriginal people. (Consumer)*

(1) Positive experiences in Aboriginal Community-controlled health services (ACCHSs)

ACCHSs are not-for-profit organisations that deliver services including comprehensive primary health care, specialist services, allied health and social support services delivered within Aboriginal and Torres Strait Islander (culturally appropriate) models of care and under Aboriginal and Torres Strait Islander governance structures. Most (but not all) participants talked about their positive experiences with ACCHSs, including their role in meeting participants needs through culturally informed experiences of healing and trust, and coordinating and navigating healthcare.

> *P3: they've helped me a lot with my personal stuff, I think our mob need to know that the help's there, go and get it. (Consumer and support person)*

> *P21: I thought [name] AMS made a big impact on us down here who were struggling to recognise one another and assist one another. (Support person)*

Participants with their own lived experience and as support people highlighted the positive impact of accessing support from ACCHSs for their mental health.

> *P10: Yes it is very helpful and that way it puts my mind at ease a little bit because I'm forever worried he's going to do something so that's one of the hardest things.* (Consumer and support person)

Within these services, participants described receiving various beneficial forms of support including peer support, medication management, counselling and psychiatric services, treatment for physical health conditions, and cultural experiences of healing including men's and women's groups and arts and associated activities.

> *P10: I like it here I do. I've been going with the women's group… and I love that. (Consumer and support person)*

> *P12: Since I've been linked up through [name] AMS I've been getting more support, being treated with respect, and spoken to like I'm welcome. (Consumer)*

> *P14: At [name] AMS the ladies are all nice to me and they made me feel like good and stuff like they were all nice. Yeah they were kind of like mums and sisters that's how I would look at it. (Consumer)*

> *P4: They're unreal, they're good mate, because they're all druggies themselves and they've all been, they know what they're talking about, they're not just people who've gone to TAFE or something to learn about it you know what I mean. They've actually walked the walk, so they can tell you mate straight to your face and you listen to them, because you're a druggie and they're a druggie. And you know yeah, and that's good. That's what I like about it. (Consumer)*

Being listened to, understood and advocated for was a key difference between Aboriginal and mainstream services. One participant described an Aboriginal officer at court who recognised that they had a problem and helped connect them with an Aboriginal service that listened and was in the process of helping them see a psychologist. Two participants identified the value of Aboriginal and non-Aboriginal services working together as part of a coordinated approach.

> *P11: I think you know us Aboriginals we get listened to a lot more than you do in the mainstream. (Consumer)*
>
> *P11: I felt like they were judgmental, and they were too busy in their own like things working and you know and doing other things to listen to what the people like me had to say that needed help you know. We'd reach out for help for a reason and we're screaming on the inside you know for help and there's no-one listening you know so what do we do we just shut down if we don't get the help we need we shut down and that's what happened to me I shut down until I got in touch with [Aboriginal health service]. (Consumer)*
>
> *P13: The woman the Aboriginal officer at the court asked me if I wanted help because she came to see me and asked me questions and she put me onto Luke and Luke rang me. She handed the paperwork into [Service name] and [Counsellor] rang me. [Counsellor]'s good he's calming, he's understanding, and he listens to me when I feel a bit off and a bit down he listens to what I have to say and tries to talk me through it. He's good, he's trying to get me help with a psychologist through [Service name]. (Consumer)*
>
> *P14: [Support person describing helping a family access the service] So once we tapped into, we worked out, it starts there with that doctor, so once the doctor is able to – and you've got to, and a lot of those doctors like if they just went to mainstream doctors they wouldn't sort of understand what the dynamics are of an Aboriginal person and if they're living with 10 people at home or whatever and. But what we did was even this mother with the son she, once she went to the doctor they hooked her into some services. (Consumer)*

(2) Racial discrimination in mainstream health services

A number of participants gave accounts of discriminatory or inappropriate treatment by staff in health services, which they assigned to stereotypical negative views of Aboriginal and Torres Strait Islander people, including those relating to use of substances of being seen as 'troublemakers'.

> *P3: These professionals, not only police, you look at the hospitals, you go to the A&E at the hospital, and they see a black fella come in, and oh here we go, yeah. And I've sat there and seen it. It's sad, I get sad when I see that, because that poor person, he or she's going there for help and they've been stereotyped, they're just, they've been looked down at, and they're not going to get the help that they want because of the attitude of that person on the other side there. (Consumer and support person)*
>
> *P5: I think that they [staff in hospitals] think, I don't know, they still think these black people they drink, they take drugs, they're no good. And I think this is what's still happening (Consumer and support person)*
>
> *P5: Yeah it's the mixture, they've got all these people in like it's ready for a bomb to go off you know. Like my wife, where was it, mainly at [Health service] I think, she ended up in a lot of arguments you know, because of people with different disabilities, you know, they're quite easily – it's volatile you know. And especially being a black woman you know, and get called names and whatever you know, you're just a troublemaker like the rest of them and all this. (Consumer and support person)*
>
> *P1: I experienced you know the very sly, very undermining, so so disrespectful to our culture. The cultural stuff was the worst, regardless of what diagnosis you had, the cultural stuff as a black person, that was a priority, they took that as a priority to treat us like fucking shit. They really segregated us, put us and treated us differently to the – like if a white person had schizophrenia and a black person had schizophrenia, the white person although their attitudes would change, but it was worse with the blackfellas. (Consumer)*
>
> *P14: I think the reception you get by not identifying as Aboriginal sometimes works out better for you because straight away if you identify as Aboriginal sometimes people start saying you're a trouble maker, you want something for free or some other crap and it's just like a stigma or something that's involved in it which isn't very fair because like when you say it it's probably because you just need some help it's not like you're actually after anything. (Consumer)*

> *P14: They look at me like, why am I saying I'm Aboriginal, but I'm not saying it so I get better help, more help or something else I identify as it because that's who I actually am you know what I mean like that's how I see myself but when other people hear you say it they think something else or the next thing they usually ask me about drugs and am I on some or do I want some or what am I after and things like this and its quite strange so often I'll have a support worker there because I'm not after anything you know like when I want help I just want help. People think there's an agenda sometimes when you're an Aboriginal person and that you don't just want help. (Consumer)*

One participant noted there was sometimes a perceived need to 'prove' their Aboriginal status/identity which influenced their willingness to engage with services.

> *P12: I've been told for ages to go there but I didn't want to because I was scared at first. Because when I went to another thing, [name] provider, they said you're gonna have to prove you're Aboriginal or something. And they started asking questions and it was like, why, am I asking for something extra? Or I'm gonna get something extra? Like I was confused, why I've got to prove that I'm Aboriginal, like am I not getting help if I'm part and just it's weird that you need to be able to identify as Aboriginal now and prove it. But it doesn't really make a difference anyway, like do you know what I mean, you don't get more or less help because you're Aboriginal or not Aboriginal. (Consumer)*

(3) Lack of cultural competency in health services

Participants spoke of mental health services as an environment that was not conducive to healing due to the infrastructure of facilities (lack of outdoor space, being locked in a room), the lack of rituals (e.g. no access to hot water for tea, no opportunity to yarn or light a fire), the lack of purpose (no activities, no ability to cook or care for others), lack of culture (food, painting) lack of connection (limited visits, no other Aboriginal and Torres Strait Islaner people), and lack of support from healthcare professionals with cultural understanding or deep listening. Some participants said their experiences were not understood, and they would be asked diagnostic questions which they could not relate to. Many participants said that healthcare professionals needed to listen better to people's experiences and needs.

> *P1: And the things that they ask you when you go to hospital..., you've got to sit there and think about what the fuck they're asking, so you've got to sift through that. And then because you don't understand what they're talking about, and what that means, you know like you sit there and think... But if a black fella came and said oh look this one's... you know what they're talking about... because he's talking my language you know. (Consumer)*
>
> *P5: I know it's there to try and help, but I think they go about it the wrong way when they're dealing with Aboriginal people. They've got no understanding of culture, how we talk, you know. (Consumer and support person)*
>
> *P11: I think really I think the mainstream they need to listen. They need to just sit down and listen to what people have to say so that they can get the right help that they need from the first bit the first start of it because if you let it go on too long before you get the right help it's hard to turn it around (Consumer)*
>
> *P7-8: Well she did say to me like if it gets worse take her into the hospital, but like I said last time, you take them in there to, what is the mental health unit [mainstream mental health facility] yeah, you know that's like going into a prison, you know. It's no, it can't be good for their health, especially black people. (Consumer and/or support people)*

Some participants mentioned that it had taken a long time to receive a formal diagnosis, or several diagnoses. Even when one was given, it was not always clear to the participant what the diagnosis meant or what the best treatment would be. The issue of late diagnosis was common in many interviews with several individuals only accepting this a potential explanation for decades of behavioural and relationship challenges. This was particularly difficult for those having to accept or incorporate a western label such as bipolar disorder as a single explanation, despite there being additional and often complex experiences and behavioural challenges. One participant highlighted that the gap in mainstream services to meet cultural need was to blame for prolonging ill health.

> *P1: But I believe that if my cultural identity, my cultural values were attended to, I don't believe that I would've remained sick as long as I have done. I've been quite ill for quite some time, and I blame the system, I don't blame my mental health illness, I blame the system. (Consumer)*

Some support people were not involved in discussions, could not get in contact with medical staff to get a better understanding of what was happening to their loved one, and received minimal or no support from Aboriginal Liaison Officers, even though they were present in the hospital.

> *P3: But yeah I don't think it's cultural awareness, I think it's just a better understanding, and listen to the families, listen to the families, listen to the carer, you've got to listen to the carer. (Consumer and support person)*

Moreover, under public hospital care, support people were left out of medical decisions involving their loved ones. A support person who worked in the hospital their son was receiving care from described how they learned through another person that their son was receiving Electroconvulsive therapy without their knowledge*.*

> *P2: And I went that's weird. So that afternoon I was due there and I said, the first thing he said to me Mum you don't care about me, they zapped my brain today and you don't even care. And I went out and I said what happened to him today, and they said oh nothing, it's all his imagination. They lied, they absolutely lied to me and lied to [their son]. They'd kept telling him he was crazy, that didn't happen to him today. And yet I'd just come from a lunch where a worker said the staff told her that had exactly happened to him that day. They just kept the brick wall up and I got no access to his file, no nothing. (F: Oh because you're) The parent, and he was a public, apparently when you're a public patient they can do what they like. So they said. (Support person)*

Further, a few support people described how their efforts to intervene early were often dismissed by services.

> *P19: Yeah, to me it was like until she actually physically hurts someone or threatened to hurt someone, they were not going to do anything, they were just going to sit back and expect me to keep calling. But I thought well why am I calling if you're not actually going to help me. So yeah, unless she says, or anyone for that matter says that yeah I've got a problem, I need help, they can't actually get it. And I think that's when they – when they get to that point down that far, you need a few people to be able to say yeah we need to get you help, and mental health needs to listen to them in that point. Because honestly it is very sad to watch someone not even know what's going on around them (Support person)*

Several participants described how mainstream services could be improved. Suggestions included health professionals needing a better understanding of Aboriginal and Torres Strait Islander people, increased efforts to make Indigenous people feel more welcome and heard, and services that helped to facilitate self-care.

(4) Negative impact of seclusion and restraint

As with non-Indigenous people, a number of people mentioned issues around seclusion and restraint, pointing to the need for Indigenous voices to join the consumer advocacy movement to address these issues, which go entirely against culturally appropriate ways of healing.

> *P1: I said fuck off, I never come here because I'm a, this is not a drug addicted centre is it. I came here because you called it mental health. Why am I locked up, why do I have to be locked in my room, why …. doors locked. You know why do I have to have the lights out at 9 o'clock, I'm an old woman, you know this is not our way. (Consumer)*
>
> *P1: And when they do go there I know for positive fact they're going to get drugged up on medication and they've got to comply to white man's ways you know. They can't go out the back and sit and yarn and talk, they've got to come inside and lock the door. Black fellas want to be sitting outside all the time, they can't do that, so all their norms, their basic norms for home are being abolished.(Consumer)*
>
> *P5: I think with Aboriginal people you can't just lock them up, even just have a unit where they can go and sit out in the garden somewhere or something you know and just sit there and talk. (Consumer and support person)*

(5) Concerns about privacy and confidentiality

Some participants raised concerns around privacy and confidentiality, including that their attendance at health services might mean that others in the community knew of their mental health problems.

> *P3: See AMS (Aboriginal Medical Service) a lot of people won't use it because they think that you know you're going to know all my details, so they're not going to use it. (Consumer and support person)*

> *P3: The medical centre there's a trust factor there, definite trust factor. Yeah, yeah, everyone's going to know my business if I go there. Or you walk in the door and you see you know Jimmy sitting there, oh fuck Jimmy's going to know I'm here for something.(Consumer and support person)*

> *P8: I also think that those people that are suffering with this, within the community, and especially the Indigenous people, they're too afraid to speak to another Indigenous person in regards to it, you know what I mean.*
> *F: Worried about confidentiality?*
> *P8: Confidentiality and all this sort of stuff yeah. And I think that could be one of the main reasons why there's not a lot, enough of us out there getting it out there, you know what I mean.*

(6) Aboriginal staff in mainstream mental health services

Participants noted the lack of Aboriginal staff in mainstream mental health services, with several suggesting a need to employ more Aboriginal staff and another suggesting it led to delayed treatment engagement Specifically several participants highlighted that Indigenous people did not always want to speak to non-Indigenous staff, and that Indigenous staff was a means of engaging more people in services and conversations around mental illness.

> *P5: Maybe it's, I don't know whether, maybe it needs to be a recruitment program to employ Aboriginal nurses or something you know…but it's got to be more Aboriginal workers in there, I don't know where they are, they're there but where are they. (Consumer and support person)*

> *P1: And that's what I mean, our cultural needs were never met, and they'll never get met you know because they may have an Aboriginal liaison officer there, that Aboriginal liaison officer is an unskilled worker that works in the hospital right across the hospital and not trained. So you constantly see it's happening. And I know from my own personal experience, you know, like I was a private patient, and I was in [hospital], and I was there for 3 months, and I never seen a black worker. (Consumer)*

> *P15: It was something from [name] provider and 9 times out of 10 they would knock on the door and [she] wouldn't answer the door because she didn't want to deal with them, because they were not Aboriginal people, and they wouldn't understand her. So that went on for quite some time, and that's why it took as long as it did to get her to get help. (Support person)*

> *P24-28: [Group discussion on staff in health services] Yeah black fellas don't talk to whites or the Indians*
> *P24-28:If you've got an Indigenous person they'll talk to him*
> *P24-28: Yeah we need more Aboriginal nurses*
> *P24-28: Workers*
> *P24-28: Mental health workers, doctors, all that you know, we really do need more of them to talk to our people you know, that's how I look at it. (Consumer and/or support people)*

5. Discussion and recommendations

5.1. Social determinants of health

Unsurprisingly, the impact of intergenerational trauma and social and economic disadvantage at individual, family and community levels were raised by participants as key issues to consider in any recommendations around addressing stigma and discrimination towards Aboriginal and Torres Strait Islander people with mental illness.[12] For Aboriginal and Torres Strait Islander people, these issues compound the distress and social and economic exclusion that all people with mental illness may experience.[3] Lack of access to adequate housing was mentioned by several participants and is an issue of particular importance, given the high rates of substandard social housing in many Aboriginal communities.[13] Negative, commonly traumatic, experiences of racism and injustice with social services and first responders, such as housing, Centrelink, the justice system and police, points to a need for cultural competence training across social services.

The exclusion, victimisation, discrimination and racism at personal, societal and institutional levels that many Aboriginal and Torres Strait Islander peoples continue to experience were also mentioned by many participants. It is well understood that racial discrimination, both interpersonal and structural, itself poses significant risks for mental health.[14] This is likely to exacerbate poor outcomes for many Aboriginal and Torres Strait Islander people with mental illness as racism continues to have a significant impact on Aboriginal and Torres Strait Islander people's decisions about when and why they seek health services and their acceptance of and adherence to treatment.

An aspect of racial stereotyping that is particularly relevant to the reduction of stigma and discrimination towards Aboriginal and Torres Strait Islander people relates to substance use. Despite the fact that many Aboriginal and Torres Strait Islander people do not drink alcohol, they are more likely to have their symptoms and behaviours ascribed simplistically or causally to substance use than mental illness. These misconceptions may worsen stigma and discrimination and contribute to poor outcomes through lack of access to appropriate treatment.[15] As in non-Indigenous people, a nationally coordinated strategy needs to address co-existing substance use and mental illness in ways that creates empathy and understanding rather than further stigmatisation.

5.2. The cultural determinants of health

The comments of many participants reinforced the need to foreground a cultural determinants of health approach to the reduction of stigma and discrimination in Aboriginal and Torres Strait Islander communities. Several participants spoke about the important role that Aboriginal and Torres Strait Islander people in their community and kinship groups had played in their care. Acceptance and support from community members and tolerance for difference (sometimes indicated by the term '*Gwange*', a non-derogatory word used in some communities to refer to a person who acts differently to the norm) and empathy were seen as cultural strengths that can play a role in tackling stigma. Participants described situations in which Aboriginal and Torres Strait Islander and non-Indigenous community members responses to homelessness and people with mental health issues differ, with Aboriginal and Torres Strait Islander people knowing each person has a story, expressing greater empathy and a willingness to help and look out for people. Related to this, the role of community advocates in ensuring access to treatment was also highlighted as being critical in helping people with mental illness access services. Some participants recounted very negative experiences of the mental health system until they were supported and advocated for by people in their communities.

However, some participants mentioned that support people themselves often lacked adequate care, understanding and support for their role in managing difficult and distressing situations related to supporting a person with a complex mental illness. Increased support and recognition of the vital role played by support people is needed .[16]

The role of traditional cultural activities was also a key theme. Many participants mentioned the importance of arts and associated activities (such as song, dance, painting and weaving), yarning, connection to country and men's and women's groups as playing a critical role in healing and recovery. As there is evidence that such activities improve social and emotional wellbeing, promote social inclusion and cohesion and increase connection to culture, such activities should be promoted as part of a stigma reduction strategy.[17]

5.3. Need for culturally appropriate community education and anti-stigma programs

The need for culturally appropriate health education and anti-stigma programs was mentioned by several participants, with a notable example being the evidence-based Aboriginal Mental Health First Aid training program. [18] Community-led, grass-roots initiatives were seen as central to such efforts. As in the consultations with non-Indigenous people, there was no consensus on whether or not to use mainstream medical and diagnostic terms. It is likely that education programs need to focus on Aboriginal conceptions of mental health and wellbeing and also incorporate some mainstream health information as appropriate. Education programs to boost the capacity to support people with either emerging or long-term mental illness were also seen as having a role, in particular to build capacity in recognising distress and navigating services. Intensive psychoeducation, particularly around issues such as post in-patient support and medication was seen as important for carers.[16] Some participants noted a need for consumer and carer advocacy groups, and indicated that leadership by Aboriginal and Torres Strait Islander peoples is central to the success of any initiatives that aim to reduce stigma and discrimination.

5.4. The need for culturally competent health services

A key theme of the consultations related to the need to ensure access to culturally competent health services. Many participants reported negative experiences in mainstream health services, including a lack of understanding of Aboriginal and Torres Strait Islander cultural interpretations of mental health and illness. For example, experiences which may be seen as symptoms of mental health problems in non-Indigenous communities may be viewed differently in Aboriginal and Torres Strait Islander communities and vice versa (e.g. hearing voices of recently departed family members would not be seen as a symptom of schizophrenia in many Aboriginal communities).

Moreover, language barriers can hinder communication and accurate assessment, and gaps in cultural knowledge and understanding can lead to misdiagnosis or delayed diagnoses. A lack of cultural competency and the attitudes of staff can have a significant impact on the cultural safety of Aboriginal and Torres Strait Islander consumers and co-workers, resulting in lower rates of access to services and poor-quality care. These are likely to further exacerbate social and economic exclusion and create distrust of mainstream services in Aboriginal and Torres Strait Islander communities.

While there is an imperative for all mental health services to be trauma-informed, this need is particularly acute in mental health services for Aboriginal and Torres Strait Islander people. This should also include an understanding of intergenerational trauma brought about by colonisation. This trauma is often compounded by social disadvantage pointing to the need for a multifaceted, multi-sectoral response to address the social determinants of Aboriginal and Torres Strait Islander mental health.

Effective care can only occur if clinicians are culturally competent and are able to interpret presenting ‘symptoms’ within the cultural context in which they occur rather than viewing the presenting person solely through the lens of Western clinical practice. This includes a focus on whole-of-life or holistic approaches, the use of appropriate communication skills to address the language barriers, good listening skills and incorporation of kin or family as part of service delivery.

Health service system structures and training that embed cultural competence are essential to reducing stigma and discrimination in health services as the general workforce does not always have the knowledge, experience or tools to effectively treat severe mental illness in an Aboriginal and/or Torres Strait Islander cultural context.

5.4.1. The role of ACCHSs

Several participants talked about positive experiences in ACCHSs, including their role in meeting participants needs through culturally informed experiences of healing and trust, and coordinating and navigating healthcare. A nationally coordinated strategy should build on the successes achieved by ACCHSs with their focus on service delivery that typically considers the physical, emotional and social needs of the whole person in the context of their family and community.[3]

Recommendations

Recommendation 12: Address stigma and discrimination towards Aboriginal and Torres Strait Islander people by:

- Ensuring that Aboriginal and Torres Strait Islander people have leadership roles in the Strategy;
- Ensuring that any actions taken under the national strategy:
    - are inclusive of Aboriginal and Torres Strait Islander peoples;
    - do no harm, and actively reduce underlying systemic disadvantage and inequality through addressing the social determinants of health;
    - take a trauma-informed approach that recognises intergenerational trauma and the trauma caused by colonisation and systemic racism;
    - take a strengths-based approach by protecting and promoting cultural determinants of health including traditional knowledge, family, culture and kinship by:
        - incorporating Aboriginal and Torres Strait Islander conceptions of social and emotional wellbeing;
        - drawing on family and kinship support structures, while ensuring there is greater access to support;
        - drawing on Aboriginal and Torres Strait Islander cultural strengths by taking an Inclusive holistic approach to healing;
        - emphasising the role of culture and connection to country in promoting good mental health (e.g. yarning, men’s groups, arts and associated activities that enhance and utilise cultural connection and practices)
    - draw on previous successful Aboriginal and Torres Strait Islander health promotion campaigns;
- Ensuring access to culturally competent health services by:
    - addressing structural racism in health services (including harmful stereotypes about substance use);
    - implementing policies and procedures to ensure accountability for instances of racism, injustice, breaches of confidentiality and substandard care;
    - increasing participation of Aboriginal and Torres Strait Islander people at all levels in the mental health workforce (including healthcare professionals, Aboriginal Liaison Officers and peer workers);
    - ensuring health providers and social service providers receive training to improve cultural competence;

  - ensuring that culturally informed practices and methods are available in addition to clinical responses;
  - building on successes achieved in other areas of Aboriginal health, including in Aboriginal Community-Controlled Health Services (ACCHSs) which are underpinned by holistic perspectives of social and emotional wellbeing;
  - listening to, acknowledging and supporting the critical roles played by carers;
  - designing health services in collaboration with local communities to include outdoor spaces, Aboriginal art and to allow local cultural practices, including rituals or celebrations.
  - Scaling up evidence-based mental health education and carer psychoeducation programs tailored to and delivered by Aboriginal and Torres Strait Islander people.
- Implementing programs that educate non-Indigenous people about Aboriginal and Torres Strait Islander people's understandings of social and emotional wellbeing and healing;
- Implementing education and anti-stigma programs in Aboriginal and Torres Strait Islander communities that:
  - are led, co-designed and delivered by Aboriginal and Torres Strait Islander people from local communities;
  - build on the strengths of Aboriginal and Torres Strait Islander people in their culturally-based inclusivity and support for all family and community members (including those with symptoms, behaviours or diagnoses of mental illness);
  - focus on bridging Aboriginal and Torres Strait Islander and mainstream understandings of mental health to empower community members to intervene early when someone becomes distressed.

5.5. Limitations

We acknowledge that interviewing participants from a limited number of Aboriginal communities, and only very few Torres Strait Islander people does not enable us to account for the diversity in views and experiences throughout Aboriginal Australia, as Aboriginal and Torres Strait Islanders comprise diverse groups of peoples who live a variety of urban, regional and remote communities. Further work at local levels is necessary to inform locally appropriate action.

References

1. Australian Bureau of Statistics. The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples. Canberra: ABS, 2015.
2. Australian Bureau of Statistics. Causes of Death, Australia, 2018. Canberra: Australian Bureau of Statistics, 2019.
3. Calma T, Dudgeon P, Bray A. Aboriginal and Torres Strait Islander Social and Emotional Wellbeing and Mental Health. *Australian Psychologist* 2017; **52**: 255-60.
4. Viner RM, Ozer EM, Denny S, et al. Adolescence and the social determinants of health. *Lancet* 2012; **379**(9826): 1641-52.
5. Department of Health. National Aboriginal and Torres Strait Islander Health Plan 2013–2023. Canberra: Commonwealth Government of Australia, 2013.
6. Australian Bureau of Statistics. National Aboriginal and Torres Strait Islander Social Survey. Canberra: ABS, 2016.
7. Slade T, Johnston A, Oakley Browne MA, Andrews G, Whiteford H. 2007 National Survey of Mental Health and Wellbeing: methods and key findings. *Aust N Z J Psychiatry* 2009; **43**(7): 594-605.
8. Australian Institute of Health and Welfare. Substance Use Among Aboriginal and Torres Strait Islander People. Canberra, Australia: Australian Institute of Health and Welfare,, 2011.
9. Lowitja Institute. Cultural Determinants roundtable - Background paper. 2014. https://www.lowitja.org.au/content/Document/PDF/Cultural-Determinants-Roundtable-Background-Paper.pdf.
10. Gee G, Dudgeon P, Schultz C, Hart A, Kelly K. Aboriginal and Torres Strait Islander social and emotional wellbeing. In P. Dudgeon, H. Milroy, & R. Walker (Eds.), Working together: Aboriginal and Torres Strait Islander mental health and wellbeing principles and practice (pp. 55–68). Canberra, Australia: Commonwealth of Australia, 2014.
11. Productivity Commission. Mental Health. Canberra: Productivity Commission, 2020.
12. Atkinson J, Nelson J, Brooks R, Atkinson C, Ryan K. Addressing individual trauma and transgenerational trauma. In P. Dudgeon, H. Milroy, & R. Walker (Eds.), Working together: Aboriginal and Torres Strait Islander mental health and wellbeing principles and practice (2nd ed., pp. 289–306). Canberra, Australia: Commonwealth of Australia: , 2014.
13. Australian Institute of Health and Welfare. Housing assistance in Australia. Canberra, Australia: Australian Institute of Health and Welfare,, 2019.
14. Priest N, Kavanagh A, Becares L, King T. Cumulative Effects of Bullying and Racial Discrimination on Adolescent Health in Australia. *J Health Soc Behav* 2019; **60**(3): 344-61.
15. Queensland Mental Health Commission. Don't Judge, and Listen: Experiences of stigma and discrimination related to problematic alcohol and other drug use. Brisbane, Australia: Queensland Mental Health Commission,, 2020.
16. Nagel T, Thompson C. The central role of Aboriginal families in motivational counselling: family support and family 'humbug'. *Australian Indigenous Health Bulletin* 2010; **10**.
17. Australian Institute of Health and Welfare. Supporting healthy communities through arts programs. Canberra, Australia: Australian Institute of Health and Welfare, 2014.
18. Day A, Casey S, Baird M, Geia L, Wanganeen R. Evaluation of the Aboriginal and Torres Strait Islander Mental Health First Aid Program. *Aust N Z J Public Health* 2021; **45**(1): 46-52.

Appendix A: Research team

University of Melbourne

- Prof Nicola Reavley, Centre for Mental Health
- Ms Judith Wright, Centre for Mental Health
- Dr Claudia Marck, Centre for Health Equity

Origin Communications

- Mr Justin Noel
- Ms Isabelle Adams
- Mr Frank Proctor

Kate Kelleher Consulting

- Ms Kate Kelleher

Prof Nicola Reavley. Email: nreavley@unimelb.edu.au, Ph: 03 9035 7628