



newparadigm

**CULTURAL DIVERSITY
AND MENTAL HEALTH**
EXPLORING MENTAL ILLNESS
THROUGH DIFFERENT LENSES

Winter 2017

THE AUSTRALIAN JOURNAL ON
PSYCHOSOCIAL REHABILITATION



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Psychiatric Disability Services
of Victoria (VICSERV)
Level 2, 22 Horne Street,
Elsternwick Victoria 3185 Australia
T 03 9519 7000, F 03 9519 7022
newparadigm@vicserv.org.au
www.vicserv.org.au

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Cover Artwork

'Springtime', Andrea Marchetti

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Contributors

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EDITORIAL

Welcome to the Winter 2017 edition of **newparadigm** – *Cultural diversity and mental health: Exploring mental illness through different lenses.*



Debra Parnell is the Policy and Communications Manager at VICSERV

In this edition we have taken up the issue of culture and inclusiveness in mental health, focusing on culture and diversity in its broadest sense and considering the barriers and approaches to creating culturally responsive mental health services.

Despite the importance of this issue, and the emphasis that has been placed on it in a number of mental health strategies and frameworks, the development of this edition and theme was not an easy task.

It will come as no surprise to many of our readers to learn that many potential contributors were too weighed down with work to provide articles or meet deadlines, and that there was significant shortfall in programs and research specifically about cultural inclusion in mental health.

As most of our contributors lament, there is a lot of work to be done in the area of cultural inclusion in mental health – not for want of willingness and awareness of the issues, but a lack of capacity to overcome the barriers and the stigma that many people of culturally, linguistically and sexually diverse communities face.

We are nonetheless very pleased to provide a thought provoking and challenging edition, presenting diverse perspectives on creating mental health services that are culturally inclusive.

A number of articles look at specific community groups and the approaches that have been adopted to address the barriers to their engagement in mental health responses.

The first of these highlights the importance of the first National LGBTI Mental Health and Suicide Prevention Strategy for addressing the heightened risk for lesbian, gay, bisexual, transgender, and intersex (LGBTI) people of mental health diagnosis, psychological distress, self-harm and suicidal ideation and suicide attempts. This landmark document not only addresses the prior invisibility of LGBTI people in strategies and policies, but also recognises the unique needs of LGBTI people and the need for structural barriers to be seen through a 'cultural' lens. While this strategy is yet to be endorsed, it is hoped that it will drive a national coordinated response, and resourcing.

A second article describes work being undertaken in Queensland to address the low engagement of Aboriginal and Torres Strait Islander peoples in the National Disability Insurance Scheme (NDIS). Two projects are described, in which Proper Way protocols were applied – processes that are community driven, based on community wishes, values and customs, and focused on building relationships and trust. They demonstrate that culturally appropriate engagement can increase the participation of Aboriginal and Torres Strait Islander peoples in the NDIS.



In this edition, we also consider broader approaches and considerations for ensuring inclusive and appropriate access to mental health services and responses for people of diverse backgrounds and experiences.

Victoria's Mental Health Complaints Commissioner, Dr Lynne Coulson Barr, outlines concerns that people of diverse background and communities may experience particular barriers and challenges in accessing, and raising concerns about their experience with, mental health services. She describes the work that her office has been doing to improve accessibility and responsiveness to a range of priority groups – Aboriginal and Torres Strait Islander peoples, people with diverse sexualities and genders, people from culturally and linguistically diverse backgrounds, people from refugee and asylum seeker backgrounds and people with disabilities.

We also welcome the article from Mental Health Council of Tasmania's Elida Matthews, who discusses the role and importance of language, and its relationship to culture and values in mental health diagnosis and service delivery. She highlights the issues for people of non-English speaking backgrounds in adjusting to Australian community norms, and to the language of mental health.

We include a further examination of language and culture, this time in relation to the language of mental illness and the impacts of labelling. Rachel McMahon draws on her lived experience of mental illness to explore how categorisation has defined her and impacted on her self-identity; discussing the questions this has raised and that she is seeking to answer in her PhD.

Finally in our Vox Pop, we are very pleased to feature the views of people operating in the multicultural mental health space on the shape and directions of culturally inclusive mental health service provision across Australia. We put a number of questions around these issues to our respondents – their responses are challenging and instructive.

We hope that you enjoy the edition and that you find its contents thought provoking and valuable.

I would like to thank the contributors who have made this a very interesting and stimulating edition of *newparadigm* and to the new Journal Editorial Group, with representatives from Community Mental Health Australia (CMHA) and each State and Territory member organisation, who have endeavored to reflect the issues and interests of the mental health sector across the country. Finally I thank the VICSERV team for their valuable assistance in the production process.

CULTURAL DIVERSITY AND MENTAL HEALTH

Exploring mental illness
through different lenses

LGBTI people in mental health and suicide prevention: a new strategy for inclusion and action



Sally Morris is National Project Coordinator of the MindOUT National LGBTI Mental Health and Suicide Prevention Project, facilitated by the National LGBTI Health Alliance

Ross Jacobs is National Coordinator – Clinical Practice and Development of QLife, the national LGBTI peer teleweb counselling service facilitated by the National LGBTI Health Alliance

The National LGBTI Mental Health and Suicide Prevention Strategy, developed by the National LGBTI Health Alliance, is a plan for strategic action to prevent mental ill-health and suicide, and promote good mental health and wellbeing for lesbian, gay, bisexual, transgender, and intersex (LGBTI) people and communities across Australia.

In the first comprehensive document of its kind in Australia, the strategy includes recommendations across the breadth of approaches in Australian mental health work including promotion, prevention, intervention, treatment and maintenance.

The purpose of the strategy is to respond effectively to LGBTI people and provide interventions to those who are at risk by addressing the structural factors that contribute to overrepresentation of LGBTI people in mental health and suicide statistics.

It also recognises that the needs of LGBTI people are unique in several ways. This includes from an individual lived experience perspective – of how being a lesbian, gay, bisexual, transgender and/or a person with an intersex variation involves frequent incidents of discrimination and minority stress. It also acknowledges how structural barriers can be seen through a 'cultural' lens and how the collective needs of LGBTI communities subgroups can be overlooked by mainstream service providers if these concerns are not actively addressed.

Invisibility in policies and strategies

In Australian policy and planning prior to the launch of this strategy, LGBTI people and communities have been relatively invisible. In all existing mental health and suicide prevention strategies, policies and frameworks, LGBTI people characteristically are given only cursory attention; often simply named as a high risk group but not at all addressed in outcomes – and thus excluded from program and project responses.

This occurs despite LGBTI people and communities being unique subpopulations in terms of risk factors for suicide and poor mental health. Australian and international research demonstrates significant concern regarding mental health outcomes and suicidal behaviours among LGBTI people. Specifically, LGBTI populations have a heightened risk of mental health diagnosis, psychological distress, self-harm, suicide ideation, and suicide attempts (National LGBTI Health Alliance, 2016a; Australian Bureau of Statistics, 2007; Dhejne C et al, 2016; Hillier L et al, 2010; Hyde Z et al, 2014; Jones T et al, 2016; Leonard W et al, 2015; Skerrett D et al, 2015; Smith E et al, 2014).

Again the policy or practices of 'treating everyone the same' obstructs help seeking and reduces the ability of services to meet the specific needs of LGBTI people.

The Fourth National Mental Health Plan – as a core document to the National Mental Health Strategy – has no explicit inclusion of LGBTI populations (Commonwealth of Australia, 2009). In the National Suicide Prevention Strategy, which guides program responses to reduce the risk, suicide support interventions for groups identified at high risk, "gay and lesbian" communities are only mentioned once with no further detail as to how strategic intervention should be implemented. Bisexual, transgender and people with intersex characteristics are excluded completely (Department of Health and Ageing, 2007, p 32). The recently released draft Fifth National Mental Health Plan also fails to include LGBTI populations in its considerations.

For many, this invisibility in mental health and suicide prevention strategies may not seem problematic, because these strategies are a 'whole of population' response to mental health and suicide. Surely, goes the assumption, a 'catch all' approach would capture LGBTI people as well?

However, the Australian population is not homogenous, and the LGBTI population itself consists of diverse people living different lives and found in all walks of life, cultures, professions, faiths, political parties and locations. This diversity makes any 'one-size fits all' approach deficient in its ability to meet individual and specific needs, including those of LGBTI people.

Invisibility in program and service delivery

Evidence demonstrates that the elevated risk of mental ill-health and suicidality among LGBTI people and communities is not related to sexuality, gender identity or intersex characteristics in and of themselves. Rather they are due to the psychological distress that can occur as a result of experiences of discrimination, prejudice, abuse and exclusion in relation to their LGBTI identity, experience or history (National LGBTI Health Alliance, 2016b; Hillier L et al, 2010; Leonard W et al, 2015; Meyer I, 2003). Current strategies therefore fail to address these underlying causes of poor mental health.

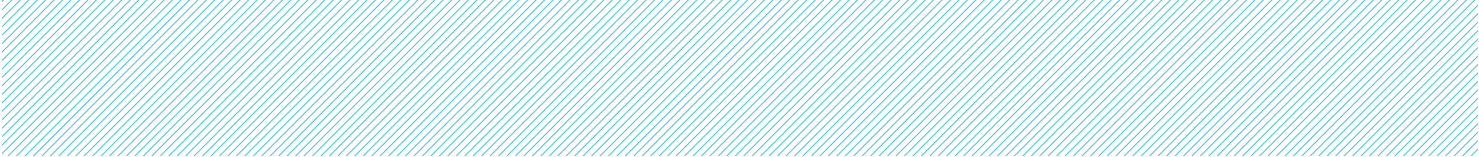
The exclusion of LGBTI populations in core strategies and policies then contributes to a culture of invisibility of LGBTI people in program and service delivery. Again the policy or practices of 'treating everyone the same' obstructs help seeking and reduces the ability of services to meet the specific needs of LGBTI people (Meyer I, 2003; Hillier L et al, 2010; Leonard W et al, 2015; McNair R & Bush R, 2015).

This lack of explicit inclusion discourages LGBTI people from accessing services and inhibits engagement in prevention and early intervention supports that aid recovery and wellness, which further contributes to poor health outcomes (Leonard W et al, 2015; McNair R & Bush R, 2015). This is despite many organisations identifying the need for inclusive practice and the progress being made in recent years towards LGBTI accessible services within the mental health and suicide prevention sectors. The absence of a clearly articulated strategic and coordinated approach to the wellbeing of LGBTI populations results in many gaps in care for LGBTI people and communities, resulting in their specific health and wellbeing needs being ignored.

Structural shortcomings and data gaps

The Australian Human Rights Commission report *Resilient Individuals: Sexual orientation, gender identity and intersex rights* (2015) outlined concerns about the adequacy of mental health services supporting LGBTI people. The report highlighted that the current Australian mental health system has fundamental structural shortcomings, preventing the system from providing adequate, inclusive and accessible services and support to LGBTI people and communities.

MindOUT argues that not only is the inclusion of LGBTI populations within mental health and suicide prevention initiatives long overdue, but essential, if targets to reduce suicide across the whole Australian population are to be achieved. We encourage specific strategic and policy interventions to address and reduce systemic stigma, prejudice and discrimination within mental health and suicide prevention services, knowing this will interrupt these known barriers for LGBTI people and communities.



MindOUT argues that not only is the inclusion of LGBTI populations within mental health and suicide prevention initiatives long overdue, but essential if targets to reduce suicide across the whole Australian population are to be achieved.

Similarly, although there is much that research tells us about the mental health of LGBTI people, it is vital to note that significant knowledge gaps remain. This is due to the lack of standardised questions regarding sex, gender, gender identity, sexuality, relationship status, and intersex status in general population research, and by data collected by mental health services about their service users (Ansara G, 2016). As data informs evidence-based policy, this exclusion has led to inaccuracy in reporting and significant underestimates. This has left LGBTI populations relatively invisible in mental health and suicide prevention policies, strategies and programmes.

It is heartening to see that despite inadequate inclusion of LGBTI populations in overarching strategies, other key mental health and suicide prevention policy documents have gone some way towards identifying the specific needs of LGBTI people and communities. LGBTI populations are slowly gaining increased recognition in mental health and suicide outcomes and this has resulted in greater inclusion in both the mental health and suicide prevention sectors.

The need for a national coordinated response

A turning point in increased recognition of LGBTI people and communities was *The Hidden Toll: Suicide in Australia* report, published by the Senate's Community Affairs Reference Committee (2010), which clearly recommended that LGBTI populations be recognised as a higher risk group in suicide prevention strategies, policies and programs. The report highlighted that LGBTI people and communities should be provided with culturally sensitive and appropriate information and services.

In response, the Commonwealth Government encouraged targeted interventions and support for LGBTI populations through community prevention activities for high risk groups. It is from this targeted initiative that, in 2011, the National LGBTI Health Alliance was tasked to deliver the MindOUT National LGBTI Mental Health and Suicide Prevention Project to support the sector to be increasingly responsive to the mental health needs of LGBTI people and communities.

...although there is much that research tells us about the mental health of LGBTI people, it is vital to note that significant knowledge gaps remain.

Despite this initiative, many national mental health and suicide prevention strategies that are fundamental to the development and implementation of mental health and suicide prevention policy and practice continue to only minimally and partially identify LGBTI people and communities as a priority group. Consequently, the mental wellbeing of LGBTI populations has not been supported by national coordinated action to implement responses that adequately support the needs of LGBTI people and communities as a priority population. This is long overdue and essential in meeting the needs of this group.

To fill this much needed gap, this new strategy has been developed to systematically address the dramatic over-representation of LGBTI people in measures of suicidality and mental ill-health. Providing a broad and practical framework that will support nationwide efforts to reduce the high incidence of suicide, suicidality, and mental illness amongst LGBTI people will lead to a more supportive and accepting society that will act as a protective factor for the mental health and wellbeing of all LGBTI Australians.

The strategy is yet to be endorsed, adopted or implemented, but requires a national coordinated response that supports efficient and effective implementation and delivery of actions across the mental health and suicide prevention sectors. Collaboration across sectors, between levels of government, and from the individual level through to the whole population is vital.

In this way, we can develop achievable goals and support them with adequate resourcing for implementation. A national commitment to this strategy is required from the Federal Government, with the allocation of appropriate resourcing to ensure that mental health and suicide prevention programs and services across Australia have clear guidance and strong support about the inclusion of LGBTI people in their care.

The National LGBTI Mental Health and Suicide Prevention Strategy can be downloaded at lgbtihealth.org.au/resources/national-lgbti-mental-health-suicide-prevention-strategy/

Strategy Principles

- **Intersectionality** – the diversity of LGBTI people and communities must be identified, acknowledged and respected with individual experiences recognised as fundamental to appropriate care.
- **Evidence** – evidence must be informed from both practice and research, and form the foundation of quality care to meet the support needs of LGBTI populations.
- **Access** – LGBTI people and communities must receive welcoming, equitable and inclusive care without encountering barriers to accessing support on the basis of their sexuality, gender, body, relationships, identities or history.
- **Lived experience** – LGBTI people and communities must be acknowledged as the experts in their own lives which have been shaped by personal and cultural history of both stigma and resilience.
- **Social inclusion** – LGBTI people and communities must be included in the fabric of Australian society through reducing discrimination, eliminating violence and removing legal barriers that affect the ability of LGBTI people to experience connection.

Strategic Goals and Actions

- 1. Inclusive and accessible care** – LGBTI people will experience equitable access to mental health and suicide prevention services and receive support that is appropriate to their experience and responsive to their needs.
- 2. Evidence, data collection and research** – An evidence base will be established about LGBTI populations that adequately represents their histories, lives, experiences, identities, relationships and accurate recording of deaths by suicide.
- 3. Recognition of diversity** – The diversity within and between LGBTI populations will be recognised and responded to with strategies and approaches that take into account their individual and unique needs.
- 4. Intersectionality and social inclusion** – LGBTI people from across all populations, backgrounds and circumstances will experience an increase in social inclusion and a reduction in stigma and discrimination.
- 5. Skilled and knowledgeable workforce** – The mental health and suicide prevention sector workforce will be knowledgeable regarding LGBTI people, and skilled, confident, and competent in responding to their support needs.
- 6. Promotion and prevention** – Mental health promotion and suicide prevention programs, activities and campaigns will address the underlying factors that compound the mental health outcomes for LGBTI populations.

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Engaging Aboriginal and Torres Strait Islander peoples in the ‘Proper Way’



Rebecca Somerville is Communication Officer for the Queensland Alliance for Mental Health (QAMH)

Adjunct Associate Professor Jennifer Cullen is Chief Executive Officer of Synapse

Dr Michelle McIntyre is Research Fellow at the The Hopkins Centre, Menzies Health Institute Queensland, Griffith University and at Synapse

Associate Professor Clare Townsend is Manager, Research and Development at Synapse

Sue Pope is Manager, Engagement and Partnerships at QAMH

The National Disability Insurance Scheme (NDIS) provides Aboriginal and Torres Strait Islander peoples with a physical, intellectual, psychosocial and/or neurocognitive disability the opportunity, for the first time, to choose and access those supports and services which they feel are culturally appropriate and which meet their needs.

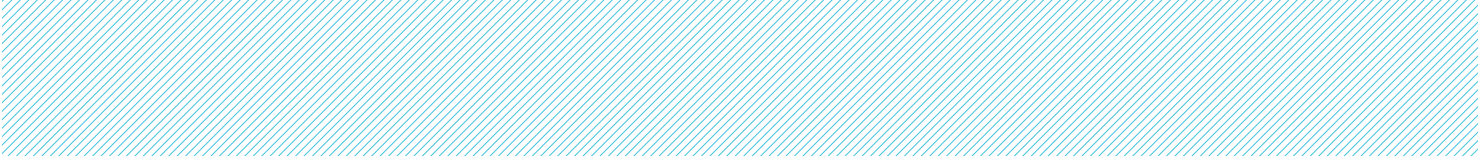
There are many barriers to Aboriginal and Torres Strait Islander peoples engaging with NDIS service providers and agencies, however. This article examines some of them and considers the cultural context in which they are experienced. It discusses Proper Way processes for engaging Aboriginal and Torres Strait Islander communities and outlines two examples of community engagement in rural and remote regions in Queensland.

Please note that in this article the term Indigenous is respectfully used to collectively refer to descendants of the original inhabitants of Australia, while acknowledging the heterogeneous nature of Aboriginal and Torres Strait Islander clans and communities.

NDIS inclusion issues for Indigenous people

In Australia, health disparities between Indigenous and non-Indigenous Australians are well documented, and Aboriginal and Torres Strait Islander peoples continue to be overly-represented in mental illness and disability populations (Australian Bureau of Statistics, 2016; Australian Institute of Health and Welfare, 2011). After taking into account age differences, the rate of disability among Aboriginal and Torres Strait Islander peoples is almost twice that of non-Indigenous people (Biddle N et al, 2012). Statistics relating to suicide, poor mental health, and substance use issues are similarly high (Department of Health and Ageing, 2013).

The reasons for these disparities are complex, but causative factors include social exclusion, racism, intergenerational trauma, and loss of land and culture (King, Smith & Gracey, 2009). Yet despite higher rates



of illness and disability, Aboriginal and Torres Strait Islander Australians are under-represented in mainstream health services (AIHW, 2011) and concerns have been raised about inequitable access to NDIS supports (Productivity Commission, 2011).

Issues relating to differing concepts of mental illness and disability, a mistrust of government services, the historical impacts of racism and intergenerational trauma, and a lack of culturally appropriate services have all been associated with a lack of access to and engagement by Indigenous Australians in mainstream health and social services (Biddle N, 2012; Gilroy J et al, 2016; Ypinazar V et al, 2007).

In contrast with the clinical focus of mainstream medical models, Aboriginal and Torres Strait Islander peoples' conceptualisations of health and wellbeing have been described as holistic, with mental, physical, cultural and spiritual health seen as indivisible (Commonwealth of Australia, 2013). Until mainstream services demonstrate an understanding of and respect for these understandings of health and disability, services will not meet the needs of Aboriginal and Torres Strait Islander peoples, and engagement levels may remain low (Wand, Eades & Corr, 2010).

Aboriginal and Torres Strait Islander peoples who are marginalised, such as through rural and remote living, homelessness, substance abuse, mental illness and/or cognitive disability, and those engaged with the criminal justice system are at an even higher risk of exclusion from the NDIS (Stephens A et al, 2014; Townsend C et al, 2017). The Department of Social Services has funded Participant Readiness activities to facilitate the inclusion of marginalised groups into the NDIS, and the Aboriginal and Torres Strait Islander Engagement Strategy outlines plans for Indigenous engagement (National Disability Insurance Agency, 2017). However, it remains unclear whether these initiatives are enough to engage Aboriginal and Torres Strait Islander peoples in the NDIS.

Engaging through Proper Way processes

The Aboriginal and Torres Strait Islander Engagement Strategy emphasises the need to engage Aboriginal and Torres Strait Islander peoples through Proper Way processes. These are named from 'proper way', a colloquial term for the carrying out of any business with Aboriginal and Torres Strait Islander peoples according to their wishes, values and customs.

Implicit in the concept of Proper Way is an understanding that Aboriginal and Torres Strait Islander peoples and communities are heterogeneous, and that protocols appropriate in one context may not be so in another.

Crucial to engaging Indigenous peoples in Proper Way is that procedures and processes must be determined by the Aboriginal and Torres Strait Islander peoples and communities involved. Indeed, any activities must be community driven and not "imposed, implied, intervened or developed with well-meaning intention from an external service system" (First Peoples Disability Network, 2010).

This can only be achieved through an approach which demonstrates cultural humility (Tervalon M & Murray-Garcia J, 1998), and builds relationships and trust over time. Establishing trust, building respectful relationships and fostering cultural understandings are crucial pre-cursors to any engagement initiatives.

Following are two models of culturally appropriate engagement with rural and remote Aboriginal and Torres Strait Islander communities that aim to enhance their understanding of and participation in the NDIS.

Peer-led NDIS Engagement Activity on Palm Island

In 2016, the QAMH worked in partnership with the Townsville-based mental health service provider Supported Options in Lifestyle and Access Services (SOLAS) to deliver a peer-led NDIS Activity on Palm Island, funded by Mental Health Australia from funding provided by the Department of Social Services.

The project sought to understand why engagement with the NDIS on Palm Island had been low, and to bring together key learnings from peer-led community consultation activities. These consultations sought to identify the opportunities, facilitators and barriers to building the capacity of the community to actively engage with the NDIS.

SOLAS has worked closely with the community of Palm Island since 2009 to support people with severe mental illness to access support services through the Federal Government-funded Personal Helpers and Mentors program (PHaMs). Services provided by SOLAS on Palm Island are delivered by local residents to ensure that support is culturally appropriate.

The project confirmed that, in communities where there may be issues of violence, substance abuse, family conflicts, unemployment and a high incidence of suicide and self-harm, many Aboriginal and Torres Strait Islander peoples are focused on addressing day-to-day aspects of their lives, not on the NDIS. It also found that there have been few resources provided to communities like Palm Island to enable the community to engage with the NDIS in a way that is meaningful to them. Moreover, where positive outcomes have been reported, resources have only supported one-off and time-limited engagement.

The Guddi Protocol has been assessed by Aboriginal and Torres Strait Islander peoples for its cultural safety and appropriateness, and could potentially be used as a basis for an NDIS assessment.

The project identified three key areas of importance for Aboriginal and Torres Strait Islander peoples on Palm Island, namely to:

- work more holistically with the whole family rather than individual participants, and provide reasonable support to empower families and build capacity to engage
- focus on NDIS engagement activities that are de-stigmatising, such as one-on-one sessions
- utilise culturally appropriate engagement methods, such as yarning and storytelling opportunities with people from the community.

Yarning and storytelling build on the Indigenous oral tradition of handing down information. Often, conversations might take the form of a story as a way of exploring a topic or responding to a question. Telling and sharing stories can be a powerful experience, yielding important information and knowledge.

A key recommendation from the project stipulated that when funding is provided for the delivery of activities on Palm Island and other Aboriginal and Torres Strait Islander communities, funding bodies must consider the context of the Aboriginal and Torres Strait Islander culture when looking at research processes and measuring outcomes. General outcome measures and research processes taken from a non-Indigenous context are not appropriate. Finally, it is important that measures of success and outcomes are developed from within the community.

The Guddi Protocol

Synapse is a non-government organisation dedicated to reconnecting the lives of people who are affected by acquired brain disorders and to building partnerships with Aboriginal and Torres Strait Islander peoples in order to build on their ideas, strengths and leadership.

The Guddi Protocol arose out of research undertaken by Synapse in far north Queensland in relation to marginalised Aboriginal and Torres Strait Islander peoples with neurocognitive disability (NCD). NCD relates to any disorder of the brain such as through acquired brain injury, dementia, alcohol and drug use, infections, and Foetal

Alcohol Syndrome Disorder (FASD). NCD can affect multiple domains including cognitive processes, psychological and physical function, as well as impacting personality and behaviour.

Discussions with services indicated a lack of culturally appropriate methods for screening for NCD and highlighted concerns about the engagement of Indigenous service users in NDIS inclusion processes.

The Guddi Protocol consists of a culturally appropriate interview which includes questions relating to thinking skills, psychosocial functioning, depression, psychosis, and post-traumatic stress disorder. The Guddi Protocol is underpinned by a 'yarning' method, which has been described as an Indigenous cultural form of conversation (Bessarab D & Ng'andu B, 2010). Yarning facilitates trust and relationship building, and represents a culturally safe method of engagement.

The Guddi Protocol has been approved by Aboriginal and Torres Strait Islander people for its cultural safety and appropriateness, and could be used as a basis for an NDIS assessment.

Proper Way protocols guided the research process during its development. Ongoing discussions with relevant Traditional Owners, Elders, and an Indigenous Research Manager/Cultural Advisor (RMCA) ensured that the research processes and materials were culturally safe and appropriate. The RMCA was embedded in the service for a three-month period in order to build relationships and liaise with relevant Elders and respected others, to ascertain research and engagement processes appropriate to this context.

At all sites where Synapse is introducing the Guddi Protocol, similar Proper Way processes are being applied. The opinions and advice of Aboriginal and Torres Strait Islander services, Elders, and respected community members inform the process. Synapse is also assisting Indigenous services to support Aboriginal and Torres Strait Islander peoples with neurocognitive disability to prepare for and access the NDIS through pre-planning activities using the Synapse Proper Way resources, and any relevant programs available in the site area.

In summary

The Guddi Protocol, and the recommendations resulting from the Peer-Led NDIS Activity Project on Palm Island, highlight the importance of undertaking engagement with Aboriginal and Torres Strait Islander communities in culturally appropriate ways. The two models demonstrate that by conducting business in the Proper Way, it is possible to increase participation of Aboriginal and Torres Strait Islander peoples in the NDIS.

The NDIS has potential to enable Aboriginal and Torres Strait Islander peoples to access supports and services to which they are entitled, providing the aforementioned engagement barriers are addressed. NDIS engagement activities must be designed with consideration of Aboriginal and Torres Strait Islander concepts of health and disability, and cultural heterogeneity, and be delivered in the Proper Way, according to community advice.

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Safeguarding rights, upholding the mental health principles and empowering consumers and carers across Victoria



Dr Lynne Coulson Barr is the Mental Health Complaints Commissioner in Victoria

The Mental Health Complaints Commissioner (MHCC) was established under the *Mental Health Act 2014* (the Act) to provide accessible, tailored and responsive complaints processes for addressing issues experienced by consumers, families and carers accessing public mental health services across Victoria, and to recommend improvements.

Since opening in 2014, we have worked to promote equitable access and safe and inclusive services for all Victorians and to improve our accessibility and responsiveness to people who contact our office.

In particular, we have focussed our efforts on engaging Aboriginal and Torres Strait Islander peoples, people with diverse sexualities and genders, people from culturally and linguistically diverse backgrounds, people from refugee and asylum seeker backgrounds, people with disabilities and young and old people. We recognise that people within these groups may experience particular barriers and challenges in raising concerns about their experience with mental health services.

Many people who contact our office are in need of a supportive process that helps them to clarify their issues and explore available options to address their concerns.

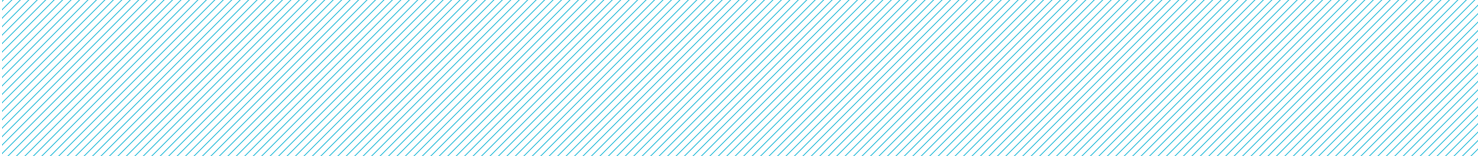
This article outlines examples of the work we have been doing to improve our accessibility and responsiveness to priority groups.

Engaging with Aboriginal and Torres Strait Islander peoples

Aboriginal and Torres Strait Islander peoples in Victoria report higher rates of psychological distress, and have higher rates of suicide and self-harm than the general population. The history of institutional and personal discrimination and exclusion that many have experienced may impact on their access to quality mental health care.

We aim to provide an effective avenue to address issues experienced by Aboriginal and Torres Strait Islander peoples in Victoria's public mental health services. We recognise the critical importance of understanding the social and cultural determinants of social and emotional wellbeing, and the provision of culturally competent services for Aboriginal and Torres Strait Islander peoples.

Over the past 12 months, we have been working to increase participation and engagement with Aboriginal and Torres Strait Islander peoples through consultations and forums, including presenting at the *Victorian Aboriginal Community Controlled Health Organisation's (VACCHO) Social and Emotional Wellbeing Conference* and its *Improving Care for Aboriginal Patients Conference*. We also participated in consultations convened by the Department of Health and Human Services on the development of Victoria's Aboriginal Health and Wellbeing Strategic Plan.



He told us that he felt his needs were not understood by his treating clinicians, and that he was not comfortable discussing his mental health concerns with a female or non-Aboriginal worker.

Recently, our team undertook VACCHO's Cultural Safety in Health Training, and we will continue to consult with both VACCHO and the Victorian Aboriginal Health Service to ensure the services we provide are safe, inclusive and engaging.

We have also begun work to develop culturally appropriate and distinct information and resources for Aboriginal and Torres Strait Islander peoples on complaints and ways in which the MHCC can assist people to raise them.

We acknowledge that there is a significant amount of work to do to achieve health equality for Aboriginal and Torres Strait Islander peoples, and we are committed to continuing our focus on developing effective engagement strategies and culturally responsive services.

The following example complaint demonstrates how we work with mental health services to ensure they uphold a person's right to receive care that recognises and responds to their distinct culture and identity. Please note we have changed details in this complaint, including the person's name, to protect the identity of all those involved.

Joshua's Story

Joshua raised his concerns with us about not being able to access culturally appropriate services as a consumer at his local community mental health service.

Joshua explained to our resolutions officer that he had asked service staff for a male Aboriginal worker to be involved in his ongoing treatment and care. He told us that he felt his needs were not understood by his treating clinicians, and that he was not comfortable discussing his mental health concerns with a female or non-Aboriginal worker. Joshua had a history of significant trauma and attempts of self-harm.

In Joshua's discussions with the service, the service manager explained that they didn't currently employ a male Aboriginal worker, and that it wasn't possible to meet his request.

We identified concerns about the service upholding the principles of the Mental Health Act 2014, including the requirement for services to recognise and respond to the distinct culture and identity of Aboriginal people receiving mental health services.

We asked the service to consider other ways that they could meet Joshua's individual needs.

We worked with both the service and Joshua to identify an Aboriginal worker in a neighbouring Aboriginal support service who Joshua felt comfortable with, and who was available to help in developing a recovery and support plan.

We also provided advice to the service on the need for their approaches to be informed by guidelines and resources for providing culturally safe and responsive services.

Respecting and celebrating diversity in sexual and gender identity

We know that when lesbian, gay, bisexual, trans, and/or intersex (LGBTI) people experience discrimination and social exclusion, this can have a negative impact on their mental health and wellbeing, as well as their access to, and use of, health services.

In 2015 we consulted with Gay and Lesbian Health Victoria and Transgender Victoria to develop an information sheet outlining the mental health principles and on how to make a complaint, to improve

accessibility and the appropriateness of the content for people who identify as LGBTI. We have continued to promote our services and to celebrate and support people from this community.

Our team has been actively involved in the Tango Project Advisory Group to build our understanding of the experiences of LGBTI elders (members of the LGTBI community aged 65 years and over). Tango Project seeks to address abuse and discrimination experienced by LGBTI elders on the basis of their sexual orientation, gender identity or intersex status.

Working with Vicdeaf has given our team a greater understanding of how we can engage consumers, carers and family members from the Deaf community about their right to speak up.

In support of the project and the Victorian Seniors Festival we joined with other Victorian commissioners, advocates and regulators for the festival's New Moves – High Tea event. The event celebrated LGBTI elders and aimed to engage with older LGBTI Victorians and to build their confidence to access information and support. It provided an opportunity for us to raise awareness of their right to make a complaint about a public mental health service, the processes they can follow, and the supporting role of our office.

In January, for the second year running, we joined the Victorian public sector at the 2017 Midsumma Pride March, where we took part in a lively and colourful celebration of difference, acceptance and equality. The event provides an opportunity for organisations, groups and individuals to recognise Victoria's LGBTI community and acknowledge the journey towards equality. It also provides an opportunity for our office to engage members of the LGBTI community and raise awareness of their right to speak up.

Improving access for people from culturally and linguistically diverse backgrounds

In the past two years we have been working hard to develop and distribute resources for Victorians from culturally and linguistically diverse backgrounds. We consulted with multicultural organisations, including the Ethnic Communities Council, and worked closely with translating services to produce an information sheet on making a complaint in the top 15 languages used through Victoria. In addition to making the [resources available online](#), we also distributed copies to 15 multicultural, transcultural and refugee and asylum resource centres and services across Victoria.

Improving access for people with disability

This year, we worked with the team from Vicdeaf to improve our understanding of the needs of Victoria's diverse Deaf community, and to produce two videos in Auslan (Australian Sign Language): [The mental health principles](#) and [Making a complaint](#). For many Victorians who are Deaf, these are likely to be the first resources they can access with information in Auslan on how to raise their concerns about an experience with a mental health service. Working with Vicdeaf has given our team a greater understanding of how we can engage consumers, carers and family members from the Deaf community about their right to speak up.

The resources complement our team's process of working with Auslan interpreters and TTY services (teletypewriter) to communicate with people who have a hearing impairment. In Victoria, over 2,700 people were recorded as Auslan users in the 2011 Australian Census. By developing these resources and making them available online, we are helping to achieve access and equity for people who are Deaf across Victoria.

Engaging with younger people through art

We recognise the importance of engaging with young people in different ways to support them in building positive relationships with mental health services, and to raise awareness of our role and their right to speak up about their concerns. In 2016 we ran The Different Faces of Mental Health project that combined art and social media to engage with young people creatively. The project provides an opportunity for young people to create masks symbolising their experience with mental health, and to speak up through a different medium.

We continued to build on this program during National Youth Week 2017, taking part in the Mind Youth Forum, where young people from Mind Australia's youth prevention and recovery care services (YPARCs) showcased masks that they had created as part of our project. The masks that were created, and the inspirational messages that the young people shared, demonstrated the important role that art can play in a person's treatment and recovery. In the lead up to Mental Health Week this year (October 8-14), we will be engaging other youth mental health services in Victoria to encourage more young consumers to share their thoughts and feelings through art.

Conclusion

Our office is a key part of the quality, safeguarding and oversight mechanisms that were established under the Act to ensure that consumers have access to safe, responsive mental health services. By responding to complaints we are able to improve experiences for individuals, and influence service and system improvements to empower consumers.

It is essential that we, and mental health services, continue to seek ways to engage with people who may experience barriers or challenges to accessing services and talking about their experiences. As we grow as an organisation we are further refining our focus on developing strategies that will progress our goal of promoting equitable access and safe and inclusive services for all Victorians and that will improve our accessibility and responsiveness to people who contact our office.

Navigating the language maze: Mental health in the context of migration



Elida Meadows is Policy Lead at the Mental Health Council of Tasmania

Language is central to a sense of who we are – our relationships with our family, our traditions and rituals, beliefs and guiding values and the way we view the world are to a large degree bound to the language(s) we speak at home.

It is critical to understand that culture and language have an impact on people from diverse cultural and linguistic backgrounds who are dealing with mental illness in Australia.

This article seeks to demonstrate that it is not simply a case of not knowing English but the deeply embedded cultural issues that go with being from a non-English-speaking culture within the existing culture of the broader Australian community.

The risk of mental health issues for migrants, refugees

Words are important in the area of mental health. To a large extent the treatment of mental health issues depends on verbal communication about symptoms and their impact on functioning. It is no good pointing to the head as you would to an injured or painful body part or region. In fact, treatment itself is often in the form of dialogue or 'talking therapy'.

When clinicians and service providers differ in cultural backgrounds from consumers, even if they speak the same language, there is a great potential for miscommunication. Obvious and less obvious forms of miscommunication and misunderstanding can lead to negative and unwanted outcomes including misgivings over treatment, drop-out from services, perception of service provider stigma and poor adherence to a treatment plan. These problems are intensified when clinicians and service providers do not speak the same language as consumers.

Migrants and refugees are at great risk of mental health issues. Many people who come to Australia are survivors of trauma such as war, natural disaster or torture. Survivors of trauma or torture are more likely to develop a mental illness, including depressive and anxiety disorders and post-traumatic stress disorder (PTSD). They may experience difficulty in concentrating, insomnia, nightmares, panic attacks, chronic pain, and feelings of powerlessness, anger, depression or guilt. Migrants may also experience 'long-distance suffering' through media reports of war or natural disasters. This occurs when people are exposed to the suffering of others in their homeland and may result in feelings of helplessness, anxiety and depression.

On top of that, new entrants may experience stress due to culture shock and the need to adjust to a society with often significantly different social structures, values, expectations, political systems, beliefs and practices. They will face challenges with the routine exigencies of everyday life – organising housing, health care, schooling and other services for their families – in an unfamiliar environment. They may not have access to support networks of friends, family, religious groups or people from their own culture.

It is probably fair to argue that lack of or limited prowess in English is the source of greatest stress and discomfort for migrants or refugees in Australia and means they cannot fully participate in English-speaking conversations. They may often feel that they sound like a nine year old in the midst of an incomprehensible conversation by a group of academics.

Where possible, it is important that interpreters with a specialised knowledge of mental health are used.

How best to use interpreters

The obvious solution for mental health services is the use of interpreters and indeed there is a legal obligation that interpreters are used in situations relating to medical and legal matters. There can be serious consequences for the person if professional interpreters are not used in these situations.

As straightforward as it may seem, there are many issues related to the use of interpreters. Even when interpreters are available, there may be difficulties with different dialects, the gender of the interpreter, or the interpreter being from a different political or ethnic background. Fears about confidentiality may also arise if the interpreter belongs to the person's own small or close-knit community. Clinical assessments for mental status examinations can pose difficulties. Even the trained interpreter and service provider may struggle with discussing and interpreting topics such as hallucination, delusions, suicide, mood changes, sexual dysfunction, and so on. Presentations of psychiatric patients, such as flight of ideas, disorganisation, tangentiality, illogical thinking, compromised speech and thought content (e.g. grandiosity, delusions, obsessions, magical thinking) are difficult to translate. Language barriers may hinder the identification of important contributors to the process of care, including stigma, shame and the person's explanatory model of illness.

Where possible, it is important that interpreters with a specialised knowledge of mental health are used. Professional interpreters have excellent bilingual language skills and are bound by a code of conduct, but those who have been trained in mental health interpreting will have a nuanced, deeper understanding of mental health concepts.

Mental health agency employees who are bilingual may be readily available and may share the person's cultural background, but this is not necessarily the best way to proceed when discussing treatment. However, bilingual staff can be used to assist communication and can be a great help with giving simple instructions or reassuring the person and their family.

Relatives, friends and colleagues of the person should only be asked to assist with communicating simple, practical messages. Apart from compromising the patient's right to privacy and the potential for embarrassment for all parties, using family members as translators

puts undue stress on everyone involved. A young child should never be used as an interpreter except in an emergency, mainly because of the high possibility of misinterpretation and a risk of great stress to the child.

When using an interpreter, it is important to follow a few simple rules when it comes to language and cultural issues and these include the use of plain English and clear enunciation of simple words and phrases that are to the point and easily translated. However, using simple words is not the same as using simplistic words and talking to the patient or the interpreter as if they are children. A person's level of language skill or accent should never be equated with level of intelligence or credibility.

A disadvantage of using a telephone language line is that the interpreter must depend on oral language alone. The interpreter cannot see the person's body language or facial expressions and must depend solely on the content and tone of the conversation. In addition, this type of interpretation is difficult to do when teaching people how to use equipment or perform a skill.

When it comes to the translation of written materials and educational programs there are several issues to consider:

- Direct translation doesn't always consider cultural influences and literacy limitations. The words used in an English version may not be appropriate or translatable for people of another culture.
- A number of new entrants don't read well in either English or their native language. It is helpful to ask an interpreter to talk with a sample of the intended population to determine if the instruction needs to be in their language or whether a simplified version in English, which includes lots of illustrations, could meet their needs just as well.
- In the design of written materials, it helps to work with representative members from the culture and language group on overall design and approach.
- If there is no access to members of the cultural group, a number of community services are becoming available to meet specific translation needs. For example, some churches and community agencies offer translation services.

A person's level of language skill or accent should never be equated with level of intelligence or credibility.

It is important to recognise that not everyone from a particular cultural or linguistic background will follow the cultural 'norms' for their particular background.

What's culture got to do with it?

Culture refers to a group's shared set of beliefs, norms, and values and language. There is abundant evidence suggesting that people who speak a language other than English at home are less represented in health services than those who speak English at home. A report by Multicultural Mental Health Australia (c 2010) found that:

- There tend to be higher rates of involuntary admissions and lower rates of voluntary admissions by consumers from culturally and linguistically diverse backgrounds.
- There are lower rates of access to community and inpatient services compared with Australian-born people. Delayed treatment can be traumatic and have a significant negative impact on the health and wellbeing of individuals and their families. It may also delay recovery rates and possibly worsen prognosis.
- Consumers from culturally and linguistically diverse backgrounds are more likely to present for treatment at the acute, crisis end of treatment which can result in longer and involuntary hospital stays.

Like all people, those from diverse cultural backgrounds have their own protective and risk factors regarding their mental health and wellbeing. Cultural beliefs and values and personal circumstances can influence whether people are motivated to seek treatment, how they cope with their symptoms, how supportive their families and communities are, where they seek help (mental health specialist, primary care provider, clergy or religious leader, community leader and/or elder), the pathways they take to get services, and how well they do in treatment.

Embarrassment or shame can result in concealment of symptoms and failure to seek treatment. In some cultures, stigma is so extreme that mental illness is thought to reflect poorly on the family and can also diminish marriage and economic prospects for other family members. Stigma also poses a challenge to research when people are reluctant to disclose the symptoms and effects of mental illness or attitudes which they have understood to be deemed socially unacceptable in this new society.

Cultural misunderstandings can occur when people don't share or understand the 'rules' of a particular culture. Cultural values determine these 'rules' about how people behave. Things to be aware of when working with people from cultural and linguistically diverse backgrounds include:

- Some people find it disrespectful to be referred to by their first names. It helps to ask a family member, friend or interpreter (where one is present) how the person would like to be addressed and, if necessary, how to pronounce their name(s).

- Use the term 'given name' rather than 'Christian name' and the term 'family name' rather than 'surname'. 'Surname' and 'family name' might have the same meaning but the term 'family name' is more easily understood by people from most cultures.
- In some cultures, individuals may appear to agree to something, saying 'yes' when they actually mean 'no' to avoid a display of disagreement and conflict. This happens quite often when working with cultures that favour politeness over frankness.
- The cultural implications of topics such as death, sexuality, childbirth, and women's health are frequently poorly understood by health care professionals, and such topics should be probed with care and respect.

It is also important to bear in mind that people from different cultural backgrounds have different styles of communication as well as different languages. These may include:

- Using a much more roundabout style, such as gradually building a picture before finally getting to the point.
- Using less powerful-sounding speech — that is, with many more hesitations, silences, prevarications ('I think', 'it seems like', 'sort of', 'actually') and/or terms of politeness ('sir', 'madam', 'please', 'with your permission').
- Talking more quietly or more submissively. This is often more pronounced in women than men, although men may also do it.

It is important to recognise that not everyone from a particular cultural or linguistic background will follow the cultural 'norms' for their particular background. Some will have adopted Anglo-Celtic Australian norms of behaving. Others may never have followed some or all of the cultural norms within their own culture.

Language of exclusion

Language excludes when words and expressions denigrate or leave out whole groups of people. Obviously racial and gender slurs create an environment in which the people targeted won't feel welcome. However, more subtle or even well-intentioned racial expressions, for example 'Australian values', can diminish and patronise.

We all need to be aware of the potential sensitivities around the use of some terminology. For example, while it may be accurate to describe someone who has recently settled in Australia as a 'migrant', this would not be appropriate after a certain period of time unless the person chooses to self-identify in that way.

Inappropriate or gratuitous references to a person's culture are to be avoided and reference to the ethnic or racial background of a person or group should only be made if it is relevant to the discussion.

The term 'Australian' should only be used to identify nationality, not to identify cultural or linguistic background. Australians are not only made up of people from Anglo-Celtic backgrounds and, indeed, there are people in Australia from Anglo-Celtic backgrounds who are not Australian.

People from culturally and linguistically diverse backgrounds are not homogenous and it is important to recognise the uniqueness of all people and avoid or making assumptions based on a person's ethnicity, religion, culture or language. There are many different cultural and ethnic groups and considerable diversity within each of these groups, as well as many other factors which affect each person's identity. While a person's cultural, ethnic, or religious identity is likely to have a significant influence, either conscious or unconscious, on their beliefs, behaviour, values and attitudes, there are a range of other factors that are relevant, including age, gender, education and socioeconomic status. Not least, a person may have a bicultural or multicultural heritage.

Service providers and clinicians need to be aware of their own personal biases and judgments and remember that learning a new language as an adult is not an easy task. Many factors can make it particularly difficult and, in some cases, almost impossible. (The Department of Education and Training (2008) in New South Wales has published useful tips and other information).

Finally, people with mental illnesses are often conceptualised as a being from a 'multicultural' population or 'overseas born' which again serves to homogenise them and is particularly inadequate when it comes to data collection and service development. As one commentator has put it:

The other challenge in research is that overseas-born Australians, although extremely diverse, are often placed into a single category – overseas born. Such studies often show that migrants have a better health status as a group. In some better studies, the overseas-born group is disaggregated into NESB (non-English speaking background) and MESB (mainly English speaking background) categories and in the most useful studies, populations are further disaggregated into regional or countries of birth groups. A recent Queensland Health study highlighted that by only examining the overseas-born as one aggregated group, many health differences are masked (Jardine A et al, 2011) which leads to a misrepresentation of migrant and refugee health (Chand M, 2012).

Role of non-verbal communication

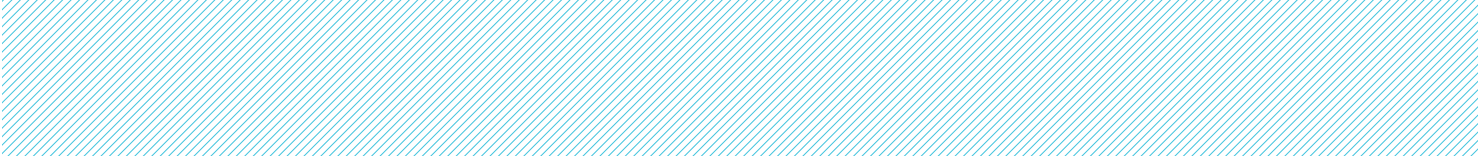
The importance of cross-cultural communication in establishing trusting relationships is not just about verbal language. While language is important to communication, especially for complex messages, actual words make up only a small proportion of the process. There are many other factors that play a part in how we communicate. In fact, these other factors can be even more powerful than words. The way we go about communicating with another person – even when we do not speak the same language – can have an enormous impact on the way we make that person feel and the way they will respond to us.

Non-verbal communication can vary significantly across different cultures, and may sometimes even have an opposite meaning. For example, maintaining eye contact is valued during interpersonal interactions in most Anglo-based cultures, and is seen as conveying trustworthiness and sincerity. However, in a number of cultures, making eye contact with someone in authority is seen as a sign of disrespect, and in some cultures eye contact between strangers may be considered shameful. Similarly, smiling or laughing in some cultures may be used when describing an event that is confusing, embarrassing or even sad.

There are also cultural differences relating to physical proximity and social distance – shaking hands and other physical contact, postures and gestures. Nodding is generally taken as a sign of understanding or agreement in mainstream Anglo-based cultures, however in some other cultures it may only signal an acknowledgment that you are speaking without implying either understanding or agreement.

People from diverse cultural backgrounds may use more, fewer or different hand gestures and body movements, and/or may find the gestures and body movements used by Anglo-Celtic Australians threatening, rude, or culturally unacceptable, to the extent that they retreat into silence or become unable to continue with their story. The way we speak – whether we speak quickly or slowly, mumble or speak clearly, where and how often we pause, whether our tone is gentle or aggressive – often says more than the words being said. Body language, our mannerisms and demeanour, including our facial expressions and gaze, all 'speak' to the other person – whether we look at or away from the other person, appear to be paying attention or not, through gestures and posture such as leaning forward or back, being relaxed or stiff, and the distance – too close or too far – that we maintain from the other person.

While it is not reasonable to expect anyone to know the range of non-verbal communication patterns across cultures, it is important to be aware of the potential for misunderstanding in these areas.



While it is not reasonable to expect anyone to know the range of non-verbal communication patterns across cultures, it is important to be aware of the potential for misunderstanding in these areas. The service provider or clinician can check if the person is showing any signs of unease or discomfort with what is being asked of them or with how it is being asked (for example, silence, evasiveness, shock, trembling, quieter voice or blushing).

It is also helpful to learn a few words of the patient's language, such as 'good morning' and 'thank you'. Taking the time to learn a few polite expressions shows an interest in the patient's language and therefore, in the person themselves. But in the final analysis, it is important to note that holistic recovery programs all over the world have found that compassionate presence is far more important than question and answer

Generational issues

Young people from different ethnic backgrounds, whether born in Australia or overseas, can feel caught between two cultures. In many cases there are particular cultural views about the roles of elders, parents, men, women and children that affect intergenerational relationships.

Parents become concerned about their authority being undermined as communication with their children becomes more difficult. Young people may become proficient in English before their parents acculturate to their new community to the extent of taking on some of the behaviours and attitudes of their peers who are part of the host culture. Language becomes an area of tension between parents and their children. On the one hand it can be useful for the new entrants to have someone in the family with a working knowledge of English. On the other hand this knowledge can drive a wedge between generations.

This can lead to a number of challenges for the family, with the parents sometimes being concerned about their child's loss of cultural identity, include their mother tongue, and a potential role reversal as the parents need to rely on the child's language proficiency to interpret and negotiate for them in various situations. Parents may feel that adoption of different values and customs represents a loss of their traditional culture and may use a stricter discipline style to counterbalance perceived permissiveness in Australian society.

Because many migrants have lost the support networks that they had in their country of origin, children may be required to take on additional responsibilities such as dealing with authorities or becoming translators for their parents. These types of situations can potentially place the child in a position of power over the parents, and at the same time expose the child prematurely to 'adult' problems in the family for which they are not emotionally or psychologically equipped.

Social isolation can be a problem for young people from non-English speaking backgrounds, with making and maintaining friendships potentially difficult due to language and cultural differences and because of bullying.

Life transitions that are part of young adult development can be more difficult to negotiate due to cultural views on sexuality, relationships, gender roles, education and employment. Difficulties with education can arise due to interruptions in schooling, language difficulties and cultural barriers.

Because of the probability of racism and bullying, children from culturally and linguistically diverse backgrounds can develop low self-esteem, which can lead to withdrawal, feeling anxious and depressed, the rejection of culture and parental values and a sense of confusion about one's identity. This can disrupt the process of integrating aspects of both the host culture and culture of origin into their lives. Stresses such as these and others can lead to withdrawal or aggressive and risk-taking behaviours, increased vulnerability to drug or alcohol problems, anxiety, depression and poor self-esteem and increased risk of suicide.

Conclusion

In summary, our beliefs, morals, customs and the rules we live by, and therefore our behaviour, are largely determined by our cultures. As these are mostly unconscious, we tend to think of them as universal, and therefore expect others to fit our expectations.

To enable us to undertake culturally safe practice when working with people from cultures other than our own, we need to be aware of our 'rules' and expectations and the fact that these are not universal but cultural.

Most people who are not from the dominant mainstream culture are migrants, and some of them are refugees. Migration and refugee experiences can have significant implications for mental health, which can be complicated by culturally unsafe practices by health professionals and service providers. Verbal and non-verbal language is our interface with people from cultural and linguistically diverse backgrounds and we need to be aware of what we are saying, both verbally and with our body language and gestures. When it comes to children of migrants and refugees, we need to appreciate that even when they speak a high level of English, they are often highly vulnerable. They require sensitive and practical support to fit into what is ultimately, despite their level of acculturation, an alien culture.

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“Measuring the unmeasurable” – looking at the culture that perpetuates mental health, its labelling, and measurement by psychiatric science



Rachael McMahon is Policy and Sector Development Officer for the Mental Health Community Coalition ACT and an Anthropology PhD candidate with the University of Wollongong

I have been living with schizo-affective disorder for over 20 years. In that time I have had periods of relative wellness and relative illness. I fight each battle as it comes. I am now trying to win my latest battle, through my PhD studies.

Basically, schizo-affective disorder is a major psychotic disorder that is like schizophrenia but with affective elements, such as depression and anxiety.

My anthropological doctoral research aims to unpack, explore and analyse what it is like to be labelled and categorised as a sub-human, sub-citizen and/or a social misfit in the context of my lived experience of having schizo-affective disorder.

My research then turns to focus on the analysis of the culture/s which perpetuate these categories and labels. The study is about making the personal political (Langellier KM, 2013). It is about giving a voice, empowering the silenced and the social outcasts, and recognising the cultural meaning and significance to which the outcasts are confined (Tuhivai-Smith L, 2012).

I am conflicted. I am labelled and categorised. All within a bio-medical culture that confines me as such, often without my input or true representation. How can I break through the cultural divide, break through the disempowerment and misrepresentation bestowed on me? Who is granted a voice in this cultural space?

This cultural space has affected me, defined me, and branded me. In this culture, I don't seem to have a choice. As a young woman (when I was diagnosed), it was through the culture of medical science that my identity was set. This identity construct disempowered me and brought me great shame, being labelled as a social misfit.

Exploring the place of culture in mental health

At this stage, 'culture' needs to be defined. Culture may be described as the dynamics of values, norms, beliefs, boundaries and meanings bestowed on a social structure. Elements of culture include language and other symbolic meanings and representation. Labelling involves symbolic meanings of the mentally ill.

Within the culture that sets boundaries of values and norms from which structured society is confined, culture defines the labels of those with a mental health disorder.

I have been stuck with and oppressed by my diagnosis and the perceived treatment I need to have, as per the decrees of mental health professionals. The suffocation of my expression, my thoughts, my essence, is perhaps the most disabling, disempowering and de-humanising experience of my life. Such stifling suppression is embedded in psychiatry, for everyone. As well, a major issue is the added marginalisation and subjugation that mental health consumers receive when they are an already marginalised and subjugated group.

I would delineate the cultural as defining the importance of what is social, and at the same time I would delineate the social as structuring what is cultural. Only a systemic analysis can come to terms with this quality of culture that escapes the individual's control (Hacking I, 1999, p 15). It is the exercise of power within culture and the social body that I am interested in (Foucault M, 1964). Indeed, as Kleinman (1988, p 25) says: "some illnesses are more modern than others and are based on more modern cultural values, for example anorexia".



How can I break through the cultural divide, break through the disempowerment and misrepresentation bestowed on me?

Culture is fundamental to power. In fact, culture is fundamentally about power. Culture tells the story of the most influential and how they became so formidable. Then how they use their strength and effectiveness to keep them in significant positions through which they can continue to dominate others. It is because of this relationship between culture and power that the sub-humans/sub-citizens/social misfits have been excluded, marginalised and rejected because of the part of the robustness in the culture.

Can we measure the seemingly unmeasurable?

Measurement is a cultural phenomenon. Measurements are a way of creating meaning and validation as cultural phenomena, creating culturally crafted facts. The power of measurements and consequent numbers are quite profound. The “magic” of numbers is enticing for those who respect and adhere to positivist scientific measurements (Lea T, 2008).

The modernist measurement process creates a space, a construction and structure for political technology, where the act of measurement forms a type of discovery which has political and governmental significance. These qualifications form part of the culture which precipitate the label of the sub-human and sub-citizen. Politics of mental health issues are supported or negated by cultural measurement. Ultimately, however, despite the persistence of and respect of science, and regarding today’s psychiatry, one is led to wonder, considering psychiatry, can we measure the seemingly unmeasurable?

The purpose of psychiatry, as a form of medical science, is to gain a scientific grasp of mental illness and of healing the mentally ill. Psychiatry also plays a cultural role, defining those with mental health disorders as a type of social class, a class that is defined as lacking. The mentally ill are stigmatised as a form of outcasts. They are not

fully human or fully citizens – they are people who don’t belong and are unwanted. This disdain is precipitated and justified by various policies of cultural significances and control, in the name of managing “anti-social behaviour” and with people classed as “stigmatised”.

Similar treatment was assigned to women, homosexual people and Indigenous peoples, also seen as not fully human or as not fully citizens, who were hunted and imprisoned, some killed like vermin. Then there were the days of Bedlam, a psychiatric institution in London, founded in 1247, where the outcasts were displayed as a freak show. Other sub-humans/sub-citizens were rounded up and put in concentration camps, reserves or institutions, like creatures to be broken and branded and put to work (Arnold C, 2008; Tuhiwai-Smith L, 2012, p 28).

Mental health professionals have measured the mentally ill with psycho-metric assessments, creating facts which aid in the broader governmentality (a term coined by philosopher Michel Foucault which refers to how the state exercises control over, or governs, its populace) of the unwell. Such assessments by mental health professionals cement the social identity of those living with a mental illness as sub-humans and sub-citizens, dependents on the state. I am in servitude to medical science, and will be for as long as I am sick, which will most likely be until I die.

The impact of labelling and governing

The psycho-metric measurements performed on me have proven to be the most significant – anthropologically, that is – in the cultural context of (dis)empowerment of the mentally ill. Today’s mental health institutions and hospitals are all about measuring and judging and surveillance. The mental health assessment tools and medical observations, cultural tools of modern psychiatry, are about measuring and judging deviance.

Today’s mental health institutions and hospitals are all about measuring and judging and surveillance.

It should be noted that it is ironic to label what we state we should not label.

After consideration from psychiatrists, psychologists, counsellors, nurses, peer support workers, a neuro-psychologist, dieticians and others, how was I pigeonholed from these measurements, when so much is riding on the use of the measurement tools? Have the many years of living with a major psychotic illness affected the function of my brain (my worst fear)? Though how much emphasis do I place on these measurements? Even when my psychiatrist and neuropsychologist have both reassured me there are so many confounding factors with the measurement tools that their results cannot be taken at face value. This makes me question the validity of measurements altogether. Yet they are still used.

It should be noted that it is ironic to label what we state we should not label. And it is equally ironic that we put so much faith in the measurement of mental health. Both of these add to the strength of the perpetuating biomedical, scientific culture. So, labeling of the mentally ill, and measuring it in the field of medicine, all add to strengthen and validate the culture that perpetuates this.

What examples or types of culture/s are we talking about? One perspective is an economic model, where the social is influenced by economic properties. Here the mentally ill are labelled as outcasts of the economy, they do not value-add a valid role. The mentally ill do not have a positive role in the economy and yet they are dependent on the state for treatment (Foucault M, 1964). I am reliant on the state for my clozapine (anti-psychotic) medication, and ultimately the state can change the law and change my medication regime. So ultimately my health can be taken away at any minute.

There are a number of questions that should be explored further, and they will be in the broader discussion of my thesis. Why is my story significant? Why should people know my story? How is my story different from others? Why am I different? What have I got to offer? Is my thesis relevant or significant? Who am I, in regards to mental health? Where am I placed? How has my disability affected my life? What differences have I made in looking at sub-humans and sub-citizens, and culture? How does my methodology succeed with this topic? How does my experience contribute to an anthropology of mental health? How does my psychosis and forthcoming thesis enculturate and situate in space and history? What are the gaps in this analysis?

Addressing these issues also includes, most importantly, an understanding as to why the mentally ill are labelled, exploring the place of culture in mental health and its power dynamics in society, and the role of measurement in psychiatry. Tackling these concerns as part of my PhD studies will help build my confidence to win another battle.

Always, there is monitoring, measuring and medicating. Always. As Biehl (2005, p 236) asserts regarding the nuances of mental illness: "It's a mystery!"

Disclaimer:

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newparadigm VOX POP

Respondents:

Vicki Katsifis, consumer and carer. Vicki is currently on the National Mental Health Commission's Consumer and Carer Engagement Project Steering Group, and works in a peer educator role at the South Eastern Sydney Recovery College

Daryl Oehm, Manager of the Victorian Transcultural Mental Health Centre (TMHC), a statewide unit, funded by the Mental Health, Drugs and Regions Division of the Victorian Department of Health and Human Services and administered by St Vincent's Hospital

Sonia Di Mezza, Deputy Chief Executive Officer at the ACT Disability, Aged and Carer Advocacy Service (ADACAS), an independent, not-for-profit, advocacy organisation helping people with disabilities, older people and their carers in the Australian Capital Territory

Dwayne Cranfield, Chief Executive Officer of the National Ethnic Disability Alliance (NEDA), the national peak organisation representing the rights and interests of people living with disability, their families and carers, from culturally and linguistically diverse and non-English speaking backgrounds

Our Vox Pop provides insights into the design and delivery of culturally inclusive mental health services.

I. Culturally inclusive mental health services have the potential to significantly improve mental health outcomes and consumer satisfaction for culturally and linguistically diverse consumers. What do you think are the vital elements of a culturally competent mental health service?

Vicki Katsifis, consumer and carer

- A strategic plan that has a section on meeting the needs of culturally and linguistically diverse communities.
- Cultural competency training to all staff to avoid stereotyping to ensure staff look at individual variation in cultural groups.
- A culture that promotes research relevant to culturally and linguistically diverse communities.
- Increased recruitment of culturally and linguistically diverse staff.
- Allocating more time to assessment and treatment for culturally and linguistically diverse clients and avoiding a 'one size fits all' approach.
- Service providers exploring their own cultural beliefs and cultural biases.
- Culturally and linguistically diverse consumer and carer participation.
- Working with cultural brokers and consultants.
- Partnering with culturally and linguistically diverse community organisations.
- Interpreters trained in mental health.

Daryl Oehm, Victorian Transcultural Mental Health Centre

The key starting point for a culturally responsive service is an osmotic relationship with the community and its demographic, as opposed to siloed service models. By this I mean that the organisation is cognisant of its internal culture and service delivery model, and has the capacity to incorporate explanatory models of health and culture that are represented in its local communities.

The essential requirement of culturally responsive organisations is acceptance that they, not the community, are responsible for practice and service models that lead to better mental health outcomes. The four key factors in culturally responsive mental health are: Reflection, Continuous Learning, Flexibility and Openness.

Sonia Di Mezza, ACT Disability, Aged and Carer Advocacy Service

The vital elements of a culturally competent health service would include the following:

- Staff who receive annual cultural competency training, so that they have the skills required to work with people from a culturally and linguistically diverse background.
- Organisations that identify and make use of bilingual staff members, who have the skills and willingness to be able to communicate with culturally and linguistically diverse consumers in their first languages.
- Staff who work for organisations that are open-minded and willing to learn about other cultures and viewpoints.

Dwayne Cranfield, National Ethnic Disability Alliance

- Information services that are formatted to be culturally in tune with the many different multicultural communities that make up Australia today.
- Information and service provision that is aware of the needs of the multicultural consumer and can service them and meet their diverse needs.
- Appropriate images, language and dialect for the target group in order to better engage them.
- Staff trained to understand that people respond differently based on their cultural background, and that often some members of communities will not use interpreting services because of confidentiality issues (trust) and may prefer a family member or friend.
- Understanding that some cultures view mental health issues through a religious lens or are very stigmatised by this and many other illnesses.
- Understanding that many cultures are fearful of government services or organisations that are bureaucratic.
- Organisations whose culture reflects the needs of the consumer, are a true partner in the process of engagement, and understand that cultural competency is more than a half day workshop for staff.

2. What do you see as the biggest challenges to improving access, responsiveness and quality of mental health services for people from culturally and linguistically diverse backgrounds?**Vicki Katsifis, consumer and carer**

- Higher rates of stigma and shame make accessing a service less likely.
- Culturally and linguistically diverse consumers are more likely to access GPs rather than mental health services.
- Language barriers make it very hard as most of the treatment and assessment options are based on communication.
- Culturally and linguistically diverse communities have different explanatory models for how they frame their mental health experiences which affects their help seeking behaviour and is challenging for clinicians.
- Lack of diversity within the mental health workforce.
- Lack of time and resources.
- The medical model can alienate culturally and linguistically diverse communities.
- An unwillingness among clinicians to use traditional healers.

Daryl Oehm, Victorian Transcultural Mental Health Centre

The key challenge to improving cultural responsiveness in mental health services is broadening the narrative pertaining to 'culturally and linguistically diverse' to one that recognises the ubiquity of culture in all forms of human association and endeavour. It should be a narrative that recognises the centrality of culture in all human interactions and as the outcome of an intersection of socio-economic, historical, religious, geographic and personal factors.

Culture is more than ethnicity and more than a generalised set of social traits, it is the outcome of human associations that give rise to numerous cultural identities formed by cultural and historical markers, communities of interest and power relationships. In essence culture is the basis of person centred care.

Sonia Di Mezza, ACT Disability, Aged and Carer Advocacy Service

The biggest challenge to improving access, responsiveness and quality of mental health services for people from culturally and linguistically diverse backgrounds would relate to their ability to access the mental health services they both want and need. Big obstacles to access include not being able to understand what mental health services are available due to language comprehension difficulties as well as cultural barriers.

Cultural barriers can be varied but are usually intrinsically linked to shame and stigma that the consumer and their community feels about having a mental health issue. Sometimes this can result in denial about the existence of an issue from the consumer and their families or communities. These feelings and beliefs go on to create great obstacles and a reluctance or fear to access the services that they require.

Dwayne Cranfield, National Ethnic Disability Alliance

Some of the challenges include:

- The demonisation of culturally and linguistically diverse communities and people by media and government and the need to change public perception of refugees, migrants, and the culturally and linguistically diverse community in general. These perceptions, when linked with mental health illnesses, make good care and support difficult to achieve.
- Ensuring that service delivery providers are a partner in the process and that support for people of culturally and linguistically diverse backgrounds is not just another revenue stream, but rather an area of passion and concern.
- Getting the multicultural community to engage with service providers. I am a strong believer in outreach work, having workers in the field engaging with consumers in their space if appropriate, such as community centres and group settings (not group therapy).
- Overcoming of their distrust and fear, awareness of the issues of mental health.

3. Can you provide example(s) of successful culturally appropriate mental health service models that are an alternative to more commonly used Western-influenced mental health service models?

Vicki Katsifis, consumer and carer, NSW

- Wellbeing forums for culturally and linguistically diverse communities in people's first language that have the presence of community elders and traditional healers. Using the word 'wellbeing' rather than referring to 'mental health' assists promotion of the event due to different explanatory models of mental illness and people not identifying with the Western medical model.
- Courses in people's first language run by bilingual educators.
- Support groups run by community leaders in people's first language.
- Involving community leaders in assessment and treatment for support and guidance.
- Partnering with cultural community organisations for projects for culturally and linguistically diverse communities that are based in the community.

Daryl Oehm, Victorian Transcultural Mental Health Centre

This requires us to broaden our concepts of 'mental health service models' and think more of wellbeing models, in that anything that supports social and emotional health is in essence a mental health model.

In the larger narrative, reducing social inequality has a positive impact on mental health. Strengthening community ties and supporting existing social capital creates positive health outcomes, as does more equal distribution of power, control and influence.

An individualistic, deficit based view of mental health and mental health interventions is often a distraction from more positive reflections on community interactions and self-help associations that contribute to prevention and promotion of mental ill health. The social determinants of health, a key component in promotion, prevention, early intervention and recovery in mental health, are relegated to a lower priority in crisis-driven mental health services.

Sonia Di Mezza, ACT Disability, Aged and Carer Advocacy Service

The Mental Health in Multicultural Australia (MHIMA) project created a Mental Health in Multicultural Australia Framework. The objective was to create a framework that organisations could use to assess their capacity and ability to provide mental health services to culturally and linguistically diverse consumers in a culturally and linguistically appropriate manner.

Although the MHIMA project was temporarily closed, due to a lack of funding, I understand that the framework received positive feedback from organisations that chose to implement it as well as through a review by an independent consultant.

Dwayne Cranfield, National Ethnic Disability Alliance

No, I can't provide examples of success from alternative models. I feel that multicultural mental health has flopped and that government is dragging the chain on it. When I ran recovery based mental health programs, the biggest issue was trying to engage multicultural communities.

I would however look to what is happening in Sweden due to their large intake of refugees and asylum seekers. It has become a very multicultural country over the past two decades.

I do feel that in Australian service providers need to utilise community radio to a greater extent, as many within the multicultural community listen regularly for their show/language. I would recommend broadcasting 30 second advertisements created by people from within the community, speaking in the relevant language, with a script such as: "How's your son?" "He's not good, I think he's very depressed, but I don't know", to be followed with information and contact details on who can help. It's not difficult to engage with community radio as a key part of the partnership process.

An abstract painting featuring a complex composition of overlapping shapes and textures. The color palette is rich and varied, including shades of teal, yellow, red, purple, and blue. The brushwork is visible and expressive, creating a sense of depth and movement. The overall effect is one of vibrant energy and intricate detail.

**Psychiatric Disability Services
of Victoria (VICSERV)**

Level 2, 22 Horne Street,
Elsternwick Victoria 3185 Australia
T 03 9519 7000 F 03 9519 7022
newparadigm@vicserv.org.au
www.vicserv.org.au