NORTHERN TERRITORY LIVED EXPERIENCE NETWORK

3rd November 2023

Co-designing a national mental health lived experience consumer peak body: a case for inclusion, representation, empowerment, and above all, equity.

Submission by the Northern Territory Lived Experience Network

Acknowledgement of country

The Northern Territory Lived Experience Network acknowledges the Traditional Owners of lands across the Northern Territory. We pay our respects to Elders past, present and emerging, and we acknowledge that sovereignty of was never ceded.

Executive summary

In this submission, we advocate for the establishment of a national mental health consumer peak body that genuinely represents people with lived and/or living experiences of mental ill-health for all Australians.

In particular, we present the case for our community, people with lived experience in the Northern Territory (NT). We include some of the most vulnerable Australians, yet we have the least ability to contribute to systems advocacy. This is because the NT has the only state or territory government that does not recognise (or support) a consumer peak body to inform the highest level of decision making.

Our submission emphasises the importance of diversity and inclusion, but above all, equity. 'Equity' to ensure the most marginalised and disadvantaged 'communities' of people with lived experience are represented and supported to meaningfully contribute to the work done by the national peak bodies.

We argue this requires a significant change in approach from traditional systemic lived experience advocacy. It requires limiting the strongest, loudest and most privileged lived experience advocates and organisations so they do not take precedence and speak for all. It requires proactively engaging with marginalised and isolated lived experience communities to ensure they have a voice through the national peak bodies.

While our submission focuses on the national consumer peak body, many of our recommendations are relevant to the establishment of the national carer peak body. We request that our recommendations are considered in the context of both.

Drawing on the values and principles of the NTLEN, we argue that both peak bodies should be trauma informed, lived experience-led, and prioritize diversity, inclusion and equity in their membership and operations. We also believe the national consumer peak body should include representation by state and territory consumer peak bodies within its governance structure (similarly for the national carer peak). This will support broader representation of lived experiences through the governance structure, as well as draw attention to the absence of a NT consumer peak body. The latter will escalate the priority to recognise and support a NT lived experience representative body/s so that our community can suitably contribute to the systemic advocacy undertaken through the national peaks.

We argue the importance of recognizing and elevating attributes and experiences that intersect with mental ill-health which increase vulnerability, and by extension 'voicelessness' and a lack of representation in systemic advocacy forums. This includes neurodivergence, substance dependence and addiction, queerness, trauma, disability (particularly intellectual disability), homelessness, incarceration, survivors of violence, Aboriginality, cultural diversity and people who live in remote and very remote areas. These are dominant attributes and experiences in the NT and they predicate our experiences of care, health and quality of life.

We highlight the significance of formal agreements for collaboration between the national consumer peak body and national carer peak body, as well as other external organizations of relevance.

We argue that paramount to such agreements is upholding the human rights of the consumer, right to self-determination and right to recovery, which we define as 'living a full and meaningful life, as defined by the person'.

We support the requirement for initial funding to establish both the national consumer peak body and carer peak body. We believe that both organisations should be established for the principle reason of providing systemic advocacy and not individual advocacy or service delivery.

As Australia's most culturally diverse state or territory, we present several additional arguments and recommendations that we deem necessary to adequately represent the needs of our population. In particular, we consider it of the utmost importance that the national peak bodies uphold and respect the values and principles of collectivist cultures, in particular Aboriginal and Torres Strait Islander people.

We argue that the consumer peak body should not exclude individuals who identify as 'consumer-carers' – i.e. those who have both experience as consumer and family member/kin to a loved one with experience of mental ill-health. This is a very common experience in the NT and we similarly argue 'consumer-carers' should not be excluded from participation in the national carer peak body. Further, we feel it is appropriate that if people identify as both, then they should have the opportunity to be members of either or both peak bodies.

Background and introduction

The establishment of a national mental health consumer peak body is a pivotal step toward amplifying the voices of those with lived and/or living experiences of mental ill-health and fostering a more inclusive, diverse, equitable and empowering mental health system. This submission draws inspiration from the principles of the NTLEN and our commitment to human rights, inclusivity, equity and community-centred approaches.

The NT makes up only 1% of the national population, yet covers 18% of Australia's landmass. Our people experience the highest rates of suicide, have the least access to services, and our burden of disease for mental illness, self-harm and addiction is nearly triple the national average. We are the only state or territory whose government does not recognise and support a representative 'consumer' advocacy body.

We have the least developed peer workforce in Australia, in 2021 becoming the last state or territory to offer the Certificate IV in Mental Health Peer Work, an achievement made possible through the advocacy of the NTLEN and its allies.

Mental health organisations in the NT have historically been hesitant to employ staff in designated lived experience positions, the clinical mental health system in particular. There has been no 'consumer' lived experience staff employed in designated roles within the NT government acute mental health system for 3 to 5 years, and the only existing designated lived experience member of staff is a 0.5 FTE carer consultant in Alice Springs.

New inpatient facilities at Royal Darwin Hospital are under construction, yet no independent lived experience engagement has been undertaken to date to inform the new facility's construction or its service model.

It is fair to say, the broader lived experience community in the NT is disempowered and excluded from the highest level of decision making.

Over the last three years, the NT Lived Experience Network has sought to create an independent, collective and representative lived experience advocacy voice for Territorians. We do not receive NT government funding (or recognition) as a 'peak body' for our advocacy and have operated in an environment that has been adversarial to meaningful lived experience engagement.

We see the creation of a national consumer peak body, as pivotal to improving the engagement of people with lived experience in the NT to inform system transformation and ongoing mental health reform. We hope that it will shine a light on the 'voicelessness' of the collective community of people with lived experience in the Northern Territory's and national mental health reform agendas.

We see the creation of a national consumer peak body as an opportunity to promote the imperative for change; to argue for investment and capacity building of Territorians to participate in systemic advocacy; and, last but not least, for meaningful and genuine partnership with the lived experience community in the NT to inform the highest level of decision making.

Without these enablers we cannot influence our collective and individual experiences of care; the adherence to human rights principles during our most vulnerable periods of unwellness; and, ultimately our quality of life.

This is the basis for our submission and throughout this document we seek to articulate the principles and strategies that we believe are essential to ensure

our population is best represented for the establishment of the national peak bodies, in particular the consumer peak body.

About the NTLEN

The NTLEN emerged in 2020 when members of the local lived experience community were empowered through two pivotal peer projects: the Darwin Peer-Led Education Pilot (led by the Northern Territory Mental Health Coalition) and the Promoting Peer Work Project (led by the Mental Health Association of Central Australia).

In a mental health landscape dearth of peer models, these projects created opportunities for our community to connect, to learn about 'recovery' together, to have our experiences witnessed and validated, and to reflect the strengths we saw within each other. Importantly, our existing (and emerging) workforce was able to access to peer work skills training for the first time.

We learned the imperative for lived experience engagement (and growth of the peer workforce) as outlined in national mental health reforms. We learned our community had the right to have a say in the highest level of decision making, the imperative to support collective advocacy movements and the existence of long-established lived experience peak bodies in other states.

Ultimately, we recognised the disadvantage our lived experience community (and lived experience workforce) was subject to because we were not afforded access to the similar capacity building opportunities or support to establish a collectivist advocacy movement.

We sought financial and in-principle support to establish an advocacy body, which was not forthcoming. Yet even in a non-receptive environment, our lived experience leaders created opportunities for our community to have a voice, even without funding or recognition.[1]

Since our inception, the NTLEN has sought to provide a collective and independent voice for Territorians with lived experience of mental ill-health and its intersection with alcohol and other drug use, trauma, suicidality, and related issues. We include individuals impacted by these issues, as well as families, carers and kin who provide love and support. Our inclusion of family,

[1] Refer to www.livedexperiencent.net/publications to view our submissions.

carers and kin is a point of difference between the NTLEN and much larger interstate consumer and carer peak bodies.

Ultimately we are a human rights-based organisation, which means we at all times privilege the rights of 'consumers'. However, we do not exclude participation by people who also identify as family, carers and kin. There are several reasons we take this approach which we feel is justified and unique to the NT context.

The NT is the most culturally diverse state or territory: 46% of our population is culturally and linguistically diverse, 26% are Indigenous. 75% of Indigenous Territorians live in remote communities, mostly in circumstances of extreme socio-economic disadvantage, and subject to heightened social determinants of health.

We make up only 1% of Australia's population, are not a financially wealthy jurisdiction and hold very little influence politically on a national scale. The federal government intervention is within living memory. The impact of colonisation, removal of children and disposition of culture and connection to land is ongoing.

We have the lowest availability of mental health services per person and experience by far the highest level of need (i.e. mental distress, addiction, homelessness, incarceration, suicide etc). It is community who carries the resultant and significant unmet need of our health system.

The NTLEN knows by virtue of our peer programs, advocacy consultations and surveys that a very high proportion of people affiliated with the NTLEN are in interchanging - or dual - 'consumer' and 'carer' roles. We feel that delineation between 'consumer' and 'carer' experiences in the NT context can be problematic.

The terms 'consumer' and 'carer' imply binary experiences, but they are also are highly 'westernised' and we believe do not reflect the collectivist cultural experience of nearly half of our population.

The social and emotional wellbeing model is integral to how we practice recovery through NTLEN peer programs. All Australians can learn from this model, but it is vital for a larger proportion of our population than anywhere else in the country. We feel it is important to take a similar approach to how we practice our advocacy.

Lastly there is a very practical reason for our inclusive approach to lived experience advocacy. We are 1% of the population covering 18% of Australia's landmass, that is reliant on Commonwealth funding.

The peak bodies for community mental health organisations (the NT Mental Health Coalition) and community alcohol and other drug service providers (the Association of Alcohol and Drug Agencies NT), each have less than three staff each. We believe that financing separate consumer and carer peak bodies in the NT is simply impractical. It would dilute the impact that a combined lived experience advocacy body could have to improve the lives of Territorians.

Representation of broader lived experiences

NTLEN's principles underscore the importance of recognizing and including a diverse range of lived experiences, acknowledging and accommodating cultural diversity and collectivist cultures ways of living, being and doing.

As mentioned, our point of difference from peak bodies in other jurisdictions, is that we seek to represent the experience and perspectives of individuals intersecting with mental health and related systems, and we do not exclude family and kin who provide love and support. We are however a human rights-based organisation and this means our advocacy is always oriented to the rights of the 'consumer'.

We acknowledge that many Territorians have their own experience of mental distress, and also provide support to a loved one – they meet the definitions of both 'consumer' and 'carer'. We advocate for people with dual experiences to have the right to be represented by either or both national peak bodies.

In alignment with the needs of our community, we seek to highlight the social determinants of health, and how this impacts the mental health and social and emotional wellbeing of people with intersectional experiences and attributes, in particular Aboriginal and Torres Strait Islander Territorians.

We argue it is essential that a culturally safe and equitable approach is central to the establishment of the consumer and carer peaks to ensure NT Aboriginal and Torres Strait Islander people have access to a representative voice in the national forum.

We also emphasize the explicit inclusion of other intersecting lived experiences and attributes which compound peoples' experiences of mental ill-health and suicidality. These include neurodivergence, substance dependence and

addiction, queerness, trauma, disability (particularly intellectual disability), homelessness, incarceration, survivors of violence, cultural diversity and people who live in remote and very remote areas.

The NTLEN's commitment to human rights and inclusivity aligns with our recommendation that the peak bodies seek to explicitly provide representation for experiences and attributes which intersect with mental health and suicidality. We believe this should be reflected in the establishment of respective peak bodies' governance structures, frameworks and objectives.

By doing so the peak bodies will adhere to principles that inclusivity extends beyond the shared experience of mental ill-health and will additionally acknowledge the impact of social determinants to health.

Inclusive membership

The NTLEN's has a commitment to inclusivity, diversity and most importantly, equity. On this basis we want to highlight the importance of adopting a flexible, reflective and proactive approach to building the membership of the national consumer peak body (and by extension, national carer peak body).

Membership should encompass individuals with lived and/or living experiences of mental ill-health, organizations representing people with these experiences, state/territory representative consumer peak bodies, and other organizations representing lived experiences that have a strong intersectionality with mental distress and suicidality.

The consumer peak body should strive to cultivate a community that is inclusive, diverse and equitable, actively seeking participation and representation from every corner of the lived experience community. We advocate strongly, that it would be poor practice for the national peak bodies to allow the most privileged and dominant lived experience advocates and organisations to speak on behalf of all. We argue that the peak bodies should prioritise, promote and actively support representation by communities who experience barriers to participation in traditional systemic advocacy forums.

Based on what we have witnessed in systemic advocacy forums, this means doing things differently. It means 'noticing who is not in the room' – which communities are not present, and therefore not represented. Recognising that their very absence means they are more vulnerable than those who found the internal and external resources to turn up and participate.

We argue that the peak bodies should monitor representation and participation of intersectional populations and continually improve their approach to improve engagement because when the needs of our most vulnerable people are met, the mental health system will safer and more inclusive for everyone.

Lived experience-led and community-centred approach

A lived experience-led approach should be the cornerstone of the consumer peak body's philosophy. NTLEN's principles highlight the importance of peer-led models of care and the active involvement of individuals with lived experience in their programs and advocacy efforts. This commitment aligns with the idea that the consumer peak body should be led by those with lived experience. By prioritizing the voices and experiences of individuals who have personally encountered mental ill-health, the consumer peak body can ensure that its initiatives are grounded in the realities of those it seeks to serve.

Furthermore, the consumer peak body should adopt a community-centred approach that values the perspectives of those it serves. Honouring individuals' rights to choose aligns with this approach, as it ensures that the body's efforts are driven by the needs and experiences of the community. Community-centred care and leadership help create an environment where mental health support is relevant, accessible, and effective for all.

Valuing diversity and promoting inclusion

Diversity and inclusion should be deeply embedded in the operational policies, processes, and procedures of the consumer peak body. This means applying principles of diversity and inclusion to areas such as Human Resourcing, Board recruitment, cultural recognition, leadership, governance arrangements, and strategic direction. NTLEN's dedication to advocating for the human rights of people intersecting with the system or unable to access the system underscores the importance of ensuring that diversity and inclusion are integral to the consumer peak body's DNA.

Inclusivity is not merely a checkbox; it is a commitment to embracing differences and fostering an environment where all individuals, regardless of their backgrounds or experiences, feel valued and heard. The consumer peak body should prioritize this commitment and proactively work to ensure that diverse perspectives are represented and respected.

Systemic advocacy over individual advocacy

The primary focus of the consumer peak body should be on systemic advocacy, advocating on behalf of diverse lived experience voices to contribute to system-wide mental health policies, programs, and reform processes. This approach is aligned with NTLEN's efforts to create change within the NT mental health and suicide prevention system. By focusing on systemic advocacy, the consumer peak body can address the root causes of issues and promote changes that benefit the broader community.

Systemic advocacy has the potential to drive transformative change within the mental health sector, ensuring that policies and programs are responsive to the diverse needs of individuals living with mental ill-health. While individual advocacy and services have their place, systemic advocacy is essential for creating lasting, large-scale change.

Initial funding for establishment

The establishment of the consumer peak body is a crucial step in advancing the representation and empowerment of individuals with lived experience. To ensure a successful launch and initial operation, it is imperative that an existing organization or organizations with an understanding of the mental health sector and lived experience movements receive initial funding on a time-limited interim basis. This funding would be instrumental in setting up the new consumer peak body, establishing the necessary infrastructure, and facilitating the co-design process.

Once the consumer peak body is operational, it should transition to independent governance arrangements. This transition ensures that the body remains accountable to its members and the broader community while maintaining financial sustainability.

Individual membership for both peak bodies

Individuals who identify as both consumers and as families, carers, and kin should be welcome to become members of both peak bodies. This approach recognizes the dual roles that many individuals play in the context of mental health. They may be consumers seeking support for their own mental health challenges while also providing care and support to family members or kin facing similar issues.

To facilitate the coordination and collaboration of both peak bodies, it is essential to create mechanisms for individuals to participate in and support the activities of each body. These mechanisms should be flexible and adaptable to cater to the unique needs and experiences of individuals with dual roles.

Formal agreements for collaboration

Collaboration between the consumer peak body, carer peak body, and external organizations is crucial for addressing common issues and achieving shared objectives. To guide and formalize these collaborative efforts, formal agreements should be developed during the establishment phase of the consumer peak body. These agreements will outline how the bodies work together, identify areas of common interest, prioritise the human rights of consumers and provide a framework for effective advocacy and support.

By setting up formal agreements, the consumer peak body can establish clear and transparent mechanisms for collaboration, ensuring that the interests and needs of its members are effectively represented and addressed.

Additional comments

To understand the unique context and challenges faced by the NTLEN and the broader NT lived experience population, it is important to consider a few additional insights:

Validation of NT Representative Lived Experience Body: NTLEN emphasizes that our organization is distinct from local suicide prevention networks. We are active service users and families striving to improve our experience of care in line with human rights. This distinction highlights the need for a representative body that addresses the specific concerns and challenges faced by the NT population.

Historic Interactions with NT MHAOD Branch: NTLEN highlights our historic interactions and communications with the NT Health, Mental Health and Alcohol and Other Drugs Branch and the Northern Territory Primary Health Network. These interactions have contributed to an unsupportive environment in which we have sought to establish a systemic voice for the NT lived experience population. Recognizing this history and the challenges it poses is critical in the design and co-development of the national consumer peak body.

Conclusion

The establishment of a national mental health lived experience consumer peak body (and carer peak body) is a crucial step in ensuring that the diverse voices of individuals with lived experience are heard and that their needs are addressed. By drawing inspiration from the principles and experiences of the NTLEN, we emphasize the importance of inclusivity, representation, empowerment and most of all equity, within the co-design process. Through the adoption of these principles, the national consumer peak body can be truly representative, inclusive, and committed to human rights and inclusivity. This submission contributes to the ongoing efforts to create a more inclusive, diverse and equitable mental health system that prioritizes the well-being and voices of those most affected by mental ill-health.