

Mental Health Alcohol and Other Drugs Branch - NT Health PO Box 40596 Casuarina NT 0811

25<sup>th</sup> August 2023

To the Executive Director,

Thank you for the opportunity to make a submission relating to the draft Northern Territory Lived Experience Framework (v1, May 2023).<sup>1</sup>

We would like to acknowledge and recognise the investment of time by the Mental Health and Alcohol and Other Drugs (MHAOD) Branch to review the body of national literature relating to lived experience engagement in order to develop the draft Framework.

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The NT Lived Experience Network has chosen to respond to two substantive aspects<sup>i</sup> of the draft Framework:

The statement that "no single lived experience advisory group or organisation can represent all perspectives due to the NT's diverse population and geographical distribution" and the implication that a representative body would adversely impact the NT Government's Local Decision-Making framework.

We fundamentally disagree with both sentiments and assert that their inclusion in the finalized NT Lived Experience Framework would be counterproductive to meaningful lived experience engagement in the NT.

We have sought support from individuals and organisations in the NT and from across Australia to support our position. These are presented as an addendum to this letter.

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We know that the NT <u>needs a lived experience representative body</u> that is supported and recognised by the NT Government. The kind of body that exists in every other state and territory of Australia<sup>2</sup> and has been promoted through national mental health reforms over the last 30 years.<sup>3</sup>

We disagree that a representative organisation cannot adequately represent the cultural diversity and geographical dispersion of its community. That is the purpose of such organisations and we are aware that Western Australia<sup>4</sup> has one of the largest lived experience representative bodies (CoMHWA).

Through our recent work, we can also demonstrate that even without specific funding to do so, the NT Lived Experience Network has the skills and ability to make trusted connections and understand the experiences of people with lived experience from across the breadth of the NT. This is illustrated in the recording 'Peer Education and Recovery in the NT', which we created in collaboration with Flinders University (go to <a href="https://www.bit.ly/ntlenpeer">www.bit.ly/ntlenpeer</a> to view).<sup>5</sup>

<sup>&</sup>lt;sup>1</sup> Draft NT Lived Experience Framework, Mental Health and Alcohol and Other Drugs Branch, NT Health – www.haveyoursay.nt.gov.au/lived-experience-framework

<sup>&</sup>lt;sup>2</sup> Importance of Lived Experience Engagement, NT Lived Experience Network - <u>www.livedexperiencent.net/our-story/</u>

<sup>&</sup>lt;sup>3</sup> Literature Review, Submission for the Review of the NT Mental Health and Related Services Act (1998), NT Lived Experience Network – www.livedexperiencent.net/publications/

<sup>&</sup>lt;sup>4</sup> The Consumers of Mental Health WA – www.comhwa.org.au/

<sup>&</sup>lt;sup>5</sup> Peer Education and Recovery in the NT, NT Lived Experience Network and Flinders University - www.bit.ly/ntlenpeer

We know that a NT lived experience representative body is required to strengthen our community's ability to <u>communicate our collective experiences and perspectives</u> – many of which are shared, despite our cultural diversity and geographical dispersion. For example, people's experience of treatment and care at the Darwin and Alice Springs Hospital inpatient facilities and people's experience of the NT justice system.<sup>6</sup>

We know that without a lived experience representative body, our community has no collective voice and we are less able to influence decisions and systemic reforms occurring at both a NT and national level.

We know that a <u>lack of recognition and resourcing</u> for a lived experience representative body has impacted our community's ability to develop local knowledge and mechanisms <u>to undertake systemic advocacy</u>. That our community's ability to build networks and communicate across regions is inhibited. That we are less able to collate and elevate shared issues as matters of public interest. That ultimately, we are less able to trigger any change in order to improve our individual and collective experience.

We know that without a representative body, we remain <u>reliant on governments and departmental staff</u> to interpret our experiences and make assumptions about our collective priorities – placing our needs and perspectives, in conflict with theirs. That because of our disproportionate power, our needs and perspectives will be outranked by theirs.

We know that all of these factors <u>impact our treatment and care</u>, <u>our human rights</u> and <u>ultimately</u>, <u>our quality of life</u>. That this is true for both individuals affected by mental distress, and their family and kin who provide love and support.

We also know that a representative lived experience body <u>will not negatively impact or intrude upon the right of remote communities to self-determination</u> through Local Decision Making. We believe that to say so, obfuscates and misrepresents the purpose of lived experience representative bodies in national mental health reforms.<sup>7</sup>

Ultimately, we know that <u>Territorians have the right</u> to an unfettered, independent and collective advocacy voice <u>that is recognized and supported by our government and its departments</u>.

In this spirit, we submit our response to the draft NT Lived Experience Framework.

In closing, we call on the NT MHAOD Branch to recognize the importance of establishing a NT lived experience representative body in the final NT Lived Experience Framework. Further that, the NT Lived Experience Network, be recognized and supported as the organisation of choice to undertake this function, given its demonstrated skills and experience connecting with and advocating on behalf of Territorians with lived experience.

Kind Regards

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<sup>&</sup>lt;sup>6</sup> Submission for the Review of the NT Mental Health and Related Services Act (1998), NT Lived Experience Network – www.livedexperiencent.net/publications/

<sup>&</sup>lt;sup>7</sup> Fifth National Mental Health and Suicide Prevention Plan (2017), Australian Government - www.mentalhealthcommission.gov.au

#### Section 1 - Introduction

(page 7)

The Framework will be implemented by each service area, region and/or organisation based on specific local needs.

#### **Section 10 - Lived Experience Participation**

(page 15)

In terms of lived experience and participation in the NT, no single lived experience advisory group or organisation can represent all perspectives due to the NT's diverse population and geographical distribution. There are multiple networks and engagements representing both regional diversity and specific population's e.g. young people, Darwin Youth Suicide Prevention Network, Darwin Region Indigenous Suicide Prevention Network, NT Lived Experience Network (NTLEN), Sabrina's Reach for Life, Dolly's Dream.

Lived experience participation is consistent with the NTG Local Decision Making (LDM) framework. LDM is a long-term initiative (to be implemented over a 10-year time frame) that will provide a pathway so that communities can have more control over their own affairs, including service delivery based on a community's aspirations and needs.

<sup>&</sup>lt;sup>1</sup> Related excerpts from the draft NT Lived Experience Framework:



Complete this form to publicly support our campaign calling on the NT Government to recognize and support a NT wide lived experience representative body.

You are only required to answer Questions 1 to 3 to submit your support.

You can choose to answer Questions 4 to 8 if you want to:

- 4) Publicly identify yourself as a person with lived experience (individual, family member/kin or unspecified).
- 5) Publicly identify your professional role and/or place of employment.
- 6) Provide your email address to the NT Lived Experience Network so that we can stay in touch about our work.
- 7) Lend your additional support to the NT Lived Experience Network to be recognized and supported by the NT Government as a NT-wide representative body.
- 8) Share your additional thoughts or comments.

^ l.	What	state	or	territory	are	you	from?	

* 2. What is your postcode?
* 3. What name would you like to be identified by?
4. Optional: Do you have lived experience? (tick all that apply)
Individual lived experience (including mental distress, addiction, trauma, suicidality)
Lived experience supporting a family member or kin
Lived experience, but prefer not to specify
5. Optional: What is your professional role and/or place of employment?
6. Optional: Provide your email address if you would like us to stay in touch.
Email Address

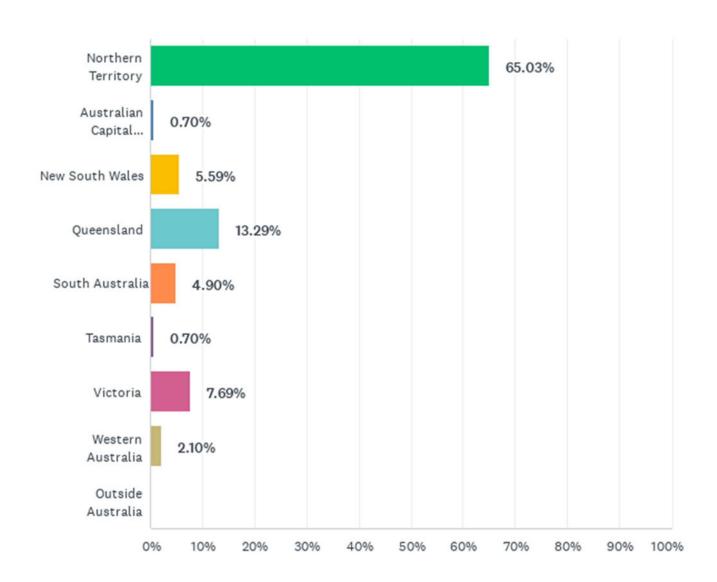
7. Optional: Check this box if you support the NT Lived Experience Network to be recognized and supported by the NT Government as a NT-wide representative body.
☐ I support
8. Optional: Additional thoughts or comments

Done



Privacy & Cookie Notice

# Q1 What state or territory are you from?



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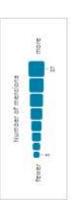
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# Q2 What is your postcode?

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19       4211       8/30/2023 11:02 AM         20       0810       8/30/2023 8:29 AM         21       5161       8/30/2023 7:15 AM         22       2720       8/30/2023 5:34 AM         23       0830       8/29/2023 10:23 PM         24       0880       8/29/2023 8:57 PM         25       0870       8/29/2023 8:39 PM         26       0810       8/29/2023 8:34 PM         27       4878       8/29/2023 5:34 PM         28       6722       8/29/2023 3:46 PM         29       0800       8/29/2023 1:09 PM         30       0810       8/29/2023 1:09 PM         31       0870       8/29/2023 11:55 AM         32       6230       8/29/2023 11:53 AM         33       3461       8/29/2023 11:29 AM         34       0810       8/29/2023 10:11 AM	17	3011	8/30/2023 12:36 PM
20       0810       8/30/2023 8:29 AM         21       5161       8/30/2023 7:15 AM         22       2720       8/30/2023 5:34 AM         23       0830       8/29/2023 10:23 PM         24       0880       8/29/2023 8:57 PM         25       0870       8/29/2023 8:33 PM         27       4878       8/29/2023 5:34 PM         28       6722       8/29/2023 3:46 PM         29       0800       8/29/2023 2:00 PM         30       0810       8/29/2023 1:08 PM         31       0870       8/29/2023 1:05 AM         32       6230       8/29/2023 11:53 AM         33       3461       8/29/2023 11:29 AM         34       0810       8/29/2023 10:11 AM	18	4518	8/30/2023 11:38 AM
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22       2720       8/30/2023 5:34 AM         23       0830       8/29/2023 10:23 PM         24       0880       8/29/2023 8:57 PM         25       0870       8/29/2023 8:33 PM         26       0810       8/29/2023 5:34 PM         27       4878       8/29/2023 5:34 PM         28       6722       8/29/2023 3:46 PM         29       0800       8/29/2023 2:00 PM         30       0810       8/29/2023 1:08 PM         31       0870       8/29/2023 11:55 AM         32       6230       8/29/2023 11:53 AM         33       3461       8/29/2023 10:11 AM         34       0810       8/29/2023 10:11 AM	20	0810	8/30/2023 8:29 AM
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24       0880       8/29/2023 8:57 PM         25       0870       8/29/2023 8:49 PM         26       0810       8/29/2023 8:33 PM         27       4878       8/29/2023 5:34 PM         28       6722       8/29/2023 3:46 PM         29       0800       8/29/2023 2:00 PM         30       0810       8/29/2023 1:08 PM         31       0870       8/29/2023 11:55 AM         32       6230       8/29/2023 11:53 AM         33       3461       8/29/2023 11:29 AM         34       0810       8/29/2023 10:11 AM	22	2720	8/30/2023 5:34 AM
25       0870       8/29/2023 8:49 PM         26       0810       8/29/2023 8:33 PM         27       4878       8/29/2023 5:34 PM         28       6722       8/29/2023 3:46 PM         29       0800       8/29/2023 2:00 PM         30       0810       8/29/2023 1:08 PM         31       0870       8/29/2023 11:55 AM         32       6230       8/29/2023 11:53 AM         33       3461       8/29/2023 11:29 AM         34       0810       8/29/2023 10:11 AM	23	0830	8/29/2023 10:23 PM
26       0810       8/29/2023 8:33 PM         27       4878       8/29/2023 5:34 PM         28       6722       8/29/2023 3:46 PM         29       0800       8/29/2023 2:00 PM         30       0810       8/29/2023 1:08 PM         31       0870       8/29/2023 11:55 AM         32       6230       8/29/2023 11:53 AM         33       3461       8/29/2023 11:29 AM         34       0810       8/29/2023 10:11 AM	24	0880	8/29/2023 8:57 PM
27       4878       8/29/2023 5:34 PM         28       6722       8/29/2023 3:46 PM         29       0800       8/29/2023 2:00 PM         30       0810       8/29/2023 1:08 PM         31       0870       8/29/2023 11:55 AM         32       6230       8/29/2023 11:53 AM         33       3461       8/29/2023 11:29 AM         34       0810       8/29/2023 10:11 AM	25	0870	8/29/2023 8:49 PM
28       6722       8/29/2023 3:46 PM         29       0800       8/29/2023 2:00 PM         30       0810       8/29/2023 1:08 PM         31       0870       8/29/2023 11:55 AM         32       6230       8/29/2023 11:53 AM         33       3461       8/29/2023 11:29 AM         34       0810       8/29/2023 10:11 AM	26	0810	8/29/2023 8:33 PM
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32       6230       8/29/2023 11:53 AM         33       3461       8/29/2023 11:29 AM         34       0810       8/29/2023 10:11 AM	30	0810	8/29/2023 1:08 PM
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34 0810 8/29/2023 10:11 AM	32	6230	8/29/2023 11:53 AM
	33	3461	8/29/2023 11:29 AM
35 5086 8/29/2023 9:54 AM	34	0810	8/29/2023 10:11 AM
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36	0820	8/29/2023 9:17 AM
37	5485	8/29/2023 8:50 AM
38	2446	8/29/2023 8:08 AM
39	0810	8/29/2023 7:56 AM
40	0810	8/28/2023 10:25 PM
41	0820	8/28/2023 9:29 PM
42	0830	8/28/2023 6:42 PM
43	0836	8/28/2023 6:33 PM
44	4500	8/28/2023 6:26 PM
45	5046	8/28/2023 5:30 PM
46	0800	8/28/2023 5:16 PM
47	0839	8/28/2023 5:09 PM
48	0820	8/28/2023 5:04 PM
49	0810	8/28/2023 4:20 PM
50	0850	8/28/2023 4:19 PM
51	0810	8/28/2023 4:04 PM
52	0838	8/28/2023 3:38 PM
53	0810	8/28/2023 3:37 PM
54	0810	8/28/2023 2:41 PM
55	0832	8/28/2023 11:49 AM
56	6157	8/28/2023 11:35 AM
57	0812	8/28/2023 11:23 AM
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59	4221	8/28/2023 10:04 AM
60	0830	8/28/2023 9:54 AM
61	3052	8/28/2023 9:04 AM
62	0832	8/28/2023 8:47 AM
63	0812	8/28/2023 8:39 AM
64	3058	8/28/2023 8:25 AM
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66	0820	8/28/2023 8:08 AM
67	0830	8/28/2023 7:21 AM
68	2914	8/28/2023 5:50 AM
69	0870	8/27/2023 11:08 PM
70	3555	8/27/2023 10:18 PM
71	0810	8/27/2023 10:12 PM
72	4810	8/27/2023 9:12 PM
73	0810	8/27/2023 8:38 PM
74	2072	8/27/2023 8:04 PM
75	4707	8/27/2023 6:16 PM
76	0810	8/27/2023 6:08 PM

77	0812	8/27/2023 5:40 PM
78	0810	8/27/2023 5:38 PM
79	0870	8/27/2023 5:21 PM
80	2290	8/27/2023 4:40 PM
81	0820	8/27/2023 4:39 PM
82	0836	8/27/2023 4:25 PM
83	0820	8/27/2023 4:21 PM
84	0830	8/27/2023 4:18 PM
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86	0835	8/27/2023 3:53 PM
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88	0820	8/27/2023 3:18 PM
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91	0830	8/27/2023 2:15 PM
92	0870	8/27/2023 1:54 PM
93	3081	8/27/2023 7:39 AM
94	0822	8/26/2023 11:18 PM
95	0812	8/26/2023 11:17 PM
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98	0812	8/26/2023 6:55 PM
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111	0834	8/26/2023 11:16 AM
112	0810	8/26/2023 11:12 AM
113	0841	8/26/2023 10:49 AM
114	0820	8/26/2023 10:44 AM
115	0810	8/26/2023 10:42 AM
116	0810	8/26/2023 10:39 AM
117	0820	8/26/2023 9:49 AM

118	3032	8/26/2023 9:48 AM
119	0810	8/26/2023 9:32 AM
120	4655	8/26/2023 9:26 AM
121	0830	8/26/2023 9:17 AM
122	4869	8/26/2023 9:08 AM
123	0810	8/26/2023 8:59 AM
124	0812	8/26/2023 8:51 AM
125	0810	8/26/2023 8:42 AM
126	0800	8/26/2023 8:37 AM
127	0812	8/26/2023 8:30 AM
128	0830	8/26/2023 8:18 AM
129	3355	8/26/2023 7:37 AM
130	0870	8/26/2023 7:28 AM
131	0830	8/26/2023 7:27 AM
132	0810	8/26/2023 4:02 AM
133	2483	8/26/2023 1:00 AM
134	0810	8/25/2023 11:42 PM
135	0812	8/25/2023 11:16 PM
136	0810	8/25/2023 11:00 PM
137	0812	8/25/2023 10:14 PM
138	2500	8/25/2023 9:40 PM
139	0830	8/25/2023 8:22 PM
140	2519	8/25/2023 8:08 PM
141	5141	8/25/2023 8:07 PM
142	0810	8/25/2023 6:44 PM
143	0800	8/25/2023 4:07 PM

## Q3 What name would you like to be identified by?

Answered: 143 Skipped: 0

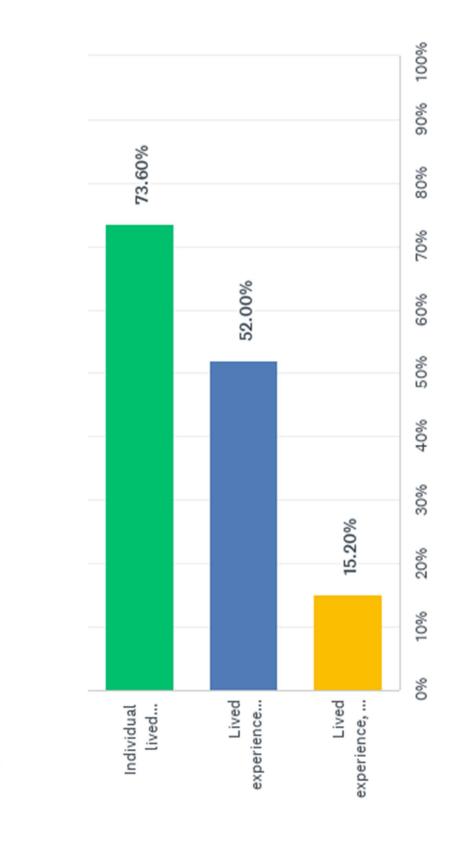
#	RESPONSES	DATE
1	Lyn Mahboub	8/31/2023 3:30 PM
2	KD	8/31/2023 1:31 PM
3	Karen	8/31/2023 1:01 PM
4	Jay Gardener	8/31/2023 12:52 PM
5	Danielle Delorme	8/31/2023 10:18 AM
6	Lewis	8/31/2023 7:47 AM
7	Zsofi de Haan	8/31/2023 7:46 AM
8	Mary de	8/31/2023 7:26 AM
9	Julia	8/31/2023 7:21 AM
10	Linda	8/31/2023 6:55 AM
11	Sandra	8/30/2023 8:24 PM
12	Rosiel Elwyn	8/30/2023 6:37 PM
13	Liz	8/30/2023 6:17 PM
14	Maureen	8/30/2023 6:15 PM
15	Sunny	8/30/2023 1:20 PM
16	Melanie Gandharba	8/30/2023 12:49 PM
17	Nick	8/30/2023 12:36 PM
18	Nicky Bright	8/30/2023 11:38 AM
19	Caroline	8/30/2023 11:02 AM
20	Lisa-Marie Wright	8/30/2023 8:29 AM
21	Suzy	8/30/2023 7:15 AM
22	Carrie Lumby	8/30/2023 5:34 AM
23	Elisabeth	8/29/2023 10:23 PM
24	Tamika Galea	8/29/2023 8:57 PM
25	Jo	8/29/2023 8:49 PM
26	Maurice Foley	8/29/2023 8:33 PM
27	Deborah Robins	8/29/2023 5:34 PM
28	Y. Malalasekara	8/29/2023 3:46 PM
29	Katherine	8/29/2023 2:00 PM
30	Imogheena Farandel	8/29/2023 1:08 PM
31	Tom	8/29/2023 11:55 AM
32	EW	8/29/2023 11:53 AM
33	Jo	8/29/2023 11:29 AM
34	Glenn	8/29/2023 10:11 AM
35	Christine	8/29/2023 9:54 AM

37         Betty         8/29/2023 8:50 AM           38         Heather Smith         8/29/2023 8:08 AM           39         James Smith         8/29/2023 7:56 AM           40         Pat Bradley         8/28/2023 10:25 PM           41         Nadere         8/28/2023 3:29 PM           42         Jen         8/28/2023 6:39 PM           43         Kate         8/28/2023 6:36 PM           44         Paula arro         8/28/2023 5:30 PM           45         Sharon Lawn         8/28/2023 5:30 PM           46         Daisy         8/28/2023 5:30 PM           47         Toni-Anne         8/28/2023 5:09 PM           48         Paulien         8/28/2023 4:09 PM           49         Michael Stevens         8/28/2023 4:09 PM           49         Michael Stevens         8/28/2023 4:09 PM           50         Les         8/28/2023 4:09 PM           51         Rex Maxwell         8/28/2023 4:09 PM           52         Bree         8/28/2023 4:09 PM           53         Roz Stevens         8/28/2023 3:38 PM           54         Connor Bramley         8/28/2023 3:31 PM           55         RobJ         8/28/2023 1:1:35 AM           56	36	Sara	8/29/2023 9:17 AM
38         Heather Smith         8/29/2023 8:08 AM           39         James Smith         8/29/2023 7:56 AM           40         Pat Bradley         8/28/2023 10:25 PM           41         Nadene         8/28/2023 6:29 PM           42         Jen         8/28/2023 6:29 PM           43         Kate         8/28/2023 6:26 PM           44         Paulu arro         8/28/2023 6:26 PM           45         Sharon Lawn         8/28/2023 5:30 PM           46         Daisy         8/28/2023 5:09 PM           47         Toni-Anne         8/28/2023 5:09 PM           48         Pauleen         8/28/2023 5:09 PM           49         Michael Stevens         8/28/2023 5:09 PM           49         Michael Stevens         8/28/2023 5:09 PM           49         Michael Stevens         8/28/2023 3:04 PM           50         Les         8/28/2023 4:20 PM           51         Rex Maxwell         8/28/2023 3:37 PM           52         Bree         8/28/2023 3:37 PM           53         RoS Stevens         8/28/2023 3:37 PM           54         Connor Bramley         8/28/2023 3:1:24 PM           55         RobJ         8/28/2023 1:35 AM <t< td=""><td></td><td></td><td></td></t<>			
40         Pat Bradley         8/28/2023 10:25 PM           41         Nadene         8/28/2023 9:29 PM           42         Jen         8/28/2023 6:42 PM           43         Kate         8/28/2023 6:33 PM           44         Paula arro         8/28/2023 5:30 PM           45         Sharon Lawn         8/28/2023 5:30 PM           46         Daisy         8/28/2023 5:09 PM           47         Toni-Anne         8/28/2023 5:09 PM           48         Pauleen         8/28/2023 5:09 PM           49         Michael Stevens         8/28/2023 5:04 PM           50         Les         8/28/2023 4:20 PM           51         Rex Maxwell         8/28/2023 4:20 PM           52         Bree         8/28/2023 4:04 PM           53         Roz Stevens         8/28/2023 3:37 PM           54         Connor Bramley         8/28/2023 3:37 PM           55         RobJ         8/28/2023 1:23 AM           56         Josie         8/28/2023 1:23 AM           57         ANNON         8/28/2023 1:23 AM           58         Noemi Tari-Keresztes         8/28/2023 1:05 AM           60         Mythily         8/28/2023 1:05 AM           61         <	38		8/29/2023 8:08 AM
41       Nadene       8/28/2023 9:29 PM         42       Jen       8/28/2023 6:42 PM         43       Kate       8/28/2023 6:33 PM         44       Paula arro       8/28/2023 6:26 PM         45       Sharon Lawn       8/28/2023 5:30 PM         46       Daisy       8/28/2023 5:16 PM         47       Toni-Anne       8/28/2023 5:09 PM         48       Pauleen       8/28/2023 5:04 PM         49       Michael Stevens       8/28/2023 4:20 PM         50       Les       8/28/2023 4:19 PM         51       Rex Maxwell       8/28/2023 4:19 PM         52       Bree       8/28/2023 3:37 PM         53       Roz Stevens       8/28/2023 3:37 PM         54       Connor Bramley       8/28/2023 3:37 PM         55       RobJ       8/28/2023 2:41 PM         56       Josie       8/28/2023 1:23 AM         57       ANNON       8/28/2023 1:23 AM         58       Noemi Tari-Keresztes       8/28/2023 1:34 AM         60       Mythily       8/28/2023 1:0:44 AM         61       Magenta Simmons       8/28/2023 9:54 AM         62       Leila       8/28/2023 8:34 AM         63       Kathy	39	James Smith	8/29/2023 7:56 AM
41       Nadene       8/28/2023 9:29 PM         42       Jen       8/28/2023 6:42 PM         43       Kate       8/28/2023 6:33 PM         44       Paula arro       8/28/2023 6:26 PM         45       Sharon Lawn       8/28/2023 5:30 PM         46       Daisy       8/28/2023 5:16 PM         47       Toni-Anne       8/28/2023 5:09 PM         48       Pauleen       8/28/2023 5:04 PM         49       Michael Stevens       8/28/2023 4:20 PM         50       Les       8/28/2023 4:19 PM         51       Rex Maxwell       8/28/2023 4:19 PM         52       Bree       8/28/2023 3:37 PM         53       Roz Stevens       8/28/2023 3:37 PM         54       Connor Bramley       8/28/2023 3:37 PM         55       RobJ       8/28/2023 2:41 PM         56       Josie       8/28/2023 1:23 AM         57       ANNON       8/28/2023 1:23 AM         58       Noemi Tari-Keresztes       8/28/2023 1:34 AM         60       Mythily       8/28/2023 1:0:44 AM         61       Magenta Simmons       8/28/2023 9:54 AM         62       Leila       8/28/2023 8:34 AM         63       Kathy	40	Pat Bradley	8/28/2023 10:25 PM
43         Kate         8/28/2023 6:33 PM           44         Paula arro         8/28/2023 6:26 PM           45         Sharon Lawn         8/28/2023 5:30 PM           46         Daisy         8/28/2023 5:16 PM           47         Toni-Anne         8/28/2023 5:09 PM           48         Pauleen         8/28/2023 5:04 PM           49         Michael Stevens         8/28/2023 4:20 PM           50         Les         8/28/2023 4:19 PM           51         Rex Maxwell         8/28/2023 4:19 PM           52         Bree         8/28/2023 3:37 PM           53         Roz Stevens         8/28/2023 3:37 PM           54         Connor Bramley         8/28/2023 2:41 PM           55         RobJ         8/28/2023 2:41 PM           56         Josie         8/28/2023 2:41 PM           57         ANNON         8/28/2023 1:3 AM           58         Noemi Tari-Keresztes         8/28/2023 1:0:51 AM           59         Lisa         8/28/2023 1:0:51 AM           60         Mythily         8/28/2023 9:04 AM           61         Magenta Simmons         8/28/2023 9:04 AM           62         Leila         8/28/2023 8:24 AM           63	41		8/28/2023 9:29 PM
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	68	Jane of Red Flag Canberra Inc. (Mental Health Action)	8/28/2023 5:50 AM
69 Jasmyn 8/27/2023 11:08 PM	69	Jasmyn	8/27/2023 11:08 PM
70 Craig Wallace 8/27/2023 10:18 PM	70	Craig Wallace	8/27/2023 10:18 PM
71 Vanessa 8/27/2023 10:12 PM	71	Vanessa	8/27/2023 10:12 PM
72 Pauline 8/27/2023 9:12 PM	72	Pauline	8/27/2023 9:12 PM
73 Julia 8/27/2023 8:38 PM	73	Julia	8/27/2023 8:38 PM
74 Sue 8/27/2023 8:04 PM	74	Sue	8/27/2023 8:04 PM
75 Sue 8/27/2023 6:16 PM	75	Sue	8/27/2023 6:16 PM
76 Donna Ashfield 8/27/2023 6:08 PM	76	Donna Ashfield	8/27/2023 6:08 PM

73         Kim Farrar         8/27/2035 5:38 PM           79         Empowering         8/27/2035 5:39 PM           80         Kerry Rock         8/27/2034 4:40 PM           81         Rohan         8/27/2034 4:40 PM           82         Sharon Price         8/27/2034 4:25 PM           83         Sharon         8/27/2034 4:25 PM           84         Claire         8/27/2034 4:18 PM           85         Himanshu         8/27/2033 3:38 PM           86         Vine Consultancy         8/27/2033 3:34 PM           87         Philippa Harris         8/27/2033 3:18 PM           88         Crystal Brunyee         8/27/2033 3:18 PM           89         Misha         8/27/2033 3:18 PM           89         Cassandra         8/27/2033 3:18 PM           91         Edited-lean         8/27/2033 3:18 PM           92         Lauren         8/27/2033 3:18 PM           93         Juliet         8/27/2033 3:18 PM           94         Tacey         8/27/2033 3:19 PM           95         Act sure         8/27/2033 3:19 PM           96         Act sure         8/27/2033 3:19 PM           97         Tabitha         8/26/2033 8:20 PM           10 <th>77</th> <th>Maria</th> <th>8/27/2023 5:40 PM</th>	77	Maria	8/27/2023 5:40 PM
79         Empowering         8277/2023 5.21 PM           80         Kerry Rock         8277/2023 4.40 PM           81         Roban         8277/2023 4.29 PM           82         Sharon Price         8277/2023 4.29 PM           83         Sharon         8277/2023 4.21 PM           84         Claire         8277/2023 4.21 PM           85         Himanshu         8277/2023 3.19 PM           86         Vinc Consultancy         8277/2023 3.19 PM           87         Philippa Harris         8272/2023 3.19 PM           89         Cystal Brunyee         8272/2023 3.19 PM           89         Misha         8272/2023 3.19 PM           90         Cassandra         8272/2023 3.19 PM           91         Billis-Jean         8272/2023 3.19 PM           92         Luuren         8272/2023 3.19 PM           93         Juliet         8272/2023 3.19 PM           94         Tacey         8262/2023 6.20 PM           95         Not sure         8262/2023 6.20 PM           96         Barbara         8262/2023 6.20 PM           97         Tabilha         8262/2023 6.50 PM           98         Harrinah Friebel         8262/2023 6.50 PM           1			
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81         Rohan         8/27/2023 4.29 PM           82         Sharon Price         8/27/2023 4.25 PM           83         Sharon         8/27/2023 4.12 PM           84         Claile         8/27/2023 4.12 PM           85         Himanshu         8/27/2023 4.16 PM           86         Vine Consultancy         8/27/2023 3.18 PM           87         Philippa Harris         8/27/2023 3.18 PM           88         Cystal Buruye         8/27/2023 3.18 PM           90         Cassandra         8/27/2023 2.28 PM           91         Billie-Jean         8/27/2023 2.15 PM           92         Lauren         8/27/2023 7.39 AM           93         Juliet         8/27/2023 2.15 PM           94         Tracey         8/27/2023 7.39 AM           95         Not sure         8/26/2023 1.11 PM           96         Barbara         8/26/2023 1.11 PM           97         Tabitha         8/26/2023 8.12 PM           98         Cali         8/26/2023 3.63 PM           99         Harnah Friebel         8/26/2023 3.63 PM           100         Monnie         8/26/2023 3.63 PM           101         None         8/26/2023 3.62 PM           102			
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107       Anon       8/26/2023 1:45 PM         108       Anngie       8/26/2023 1:06 PM         109       Liz       8/26/2023 1:04 PM         110       shorty       8/26/2023 12:45 PM         111       Kate       8/26/2023 11:16 AM         112       Liz       8/26/2023 11:12 AM         113       Tracy       8/26/2023 10:49 AM         114       11       8/26/2023 10:44 AM         115       Charles       8/26/2023 10:42 AM         116       Leanne Melling       8/26/2023 10:39 AM			
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109       Liz       8/26/2023 1:04 PM         110       shorty       8/26/2023 12:45 PM         111       Kate       8/26/2023 11:16 AM         112       Liz       8/26/2023 11:12 AM         113       Tracy       8/26/2023 10:49 AM         114       11       8/26/2023 10:44 AM         115       Charles       8/26/2023 10:42 AM         116       Leanne Melling       8/26/2023 10:39 AM			
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111       Kate       8/26/2023 11:16 AM         112       Liz       8/26/2023 11:12 AM         113       Tracy       8/26/2023 10:49 AM         114       11       8/26/2023 10:44 AM         115       Charles       8/26/2023 10:42 AM         116       Leanne Melling       8/26/2023 10:39 AM			
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113       Tracy       8/26/2023 10:49 AM         114       11       8/26/2023 10:44 AM         115       Charles       8/26/2023 10:42 AM         116       Leanne Melling       8/26/2023 10:39 AM			
114       11       8/26/2023 10:44 AM         115       Charles       8/26/2023 10:42 AM         116       Leanne Melling       8/26/2023 10:39 AM			
115       Charles       8/26/2023 10:42 AM         116       Leanne Melling       8/26/2023 10:39 AM			
116 Leanne Melling 8/26/2023 10:39 AM			
117 Mswc101 8/26/2023 9:49 AM	116		8/26/2023 10:39 AM
	117	Mswc101	8/26/2023 9:49 AM

118	Xenia	8/26/2023 9:48 AM
119	Grant	8/26/2023 9:32 AM
120	Sarah Reed	8/26/2023 9:26 AM
121	Ellie	8/26/2023 9:17 AM
122	Ailsa	8/26/2023 9:08 AM
123	denis crute	8/26/2023 8:59 AM
124	Tahlee	8/26/2023 8:51 AM
125	Abbie	8/26/2023 8:42 AM
126	Peta Mantell	8/26/2023 8:37 AM
127	Tim	8/26/2023 8:30 AM
128	Rae	8/26/2023 8:18 AM
129	Kylie	8/26/2023 7:37 AM
130	Sarah	8/26/2023 7:28 AM
131	Gabz	8/26/2023 7:27 AM
132	Popi	8/26/2023 4:02 AM
133	Fay Jackson	8/26/2023 1:00 AM
134	Louise	8/25/2023 11:42 PM
135	Mandy	8/25/2023 11:16 PM
136	Clare	8/25/2023 11:00 PM
137	Jess	8/25/2023 10:14 PM
138	Sophie	8/25/2023 9:40 PM
139	Kelli	8/25/2023 8:22 PM
140	Tim Heffernan	8/25/2023 8:08 PM
141	Bec	8/25/2023 8:07 PM
142	Sam	8/25/2023 6:44 PM
143	Sass	8/25/2023 4:07 PM

Q4 Optional: Do you have lived experience? (tick all that apply)



# Q5 Optional: What is your professional role and/or place of employment?

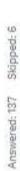
Answered: 109 Skipped: 34

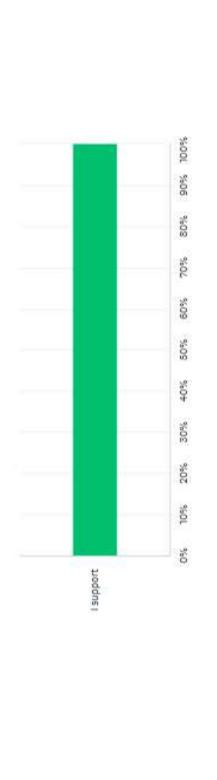
#	RESPONSES	DATE
1	Lived Experience Academic, Independent Consumer Consultant, Advocate, Educator and more	8/31/2023 3:30 PM
2	Support worker	8/31/2023 1:01 PM
3	Lived Experience Coordiantor, COORDINARE	8/31/2023 12:52 PM
4	Lived Experience Peer Worker, Queensland Health	8/31/2023 10:18 AM
5	Psychologist - Central Australian Aboriginal Congress	8/31/2023 7:47 AM
6	No-executive Board Director	8/31/2023 7:46 AM
7	Currently an Equine Assisted Learning Practitioner, but formerly responsible for LE inclusion in the SA Office of the Chief Psychiatrist and SA Mental Health Commission. Currently also working on a LE Framework for DVA.	8/31/2023 7:21 AM
8	Does a volunteer role count ? I hope so!	8/31/2023 6:55 AM
9	Professional researcher, Lived experience researcher, and consumer consultant	8/30/2023 6:37 PM
10	Student	8/30/2023 6:17 PM
11	Pensioner	8/30/2023 6:15 PM
12	Mental Health Peer Support Worker - QLD Health	8/30/2023 1:20 PM
13	Social Worker, Griffith University & Co Chair - Lived Experience Academic Research Network	8/30/2023 11:38 AM
14	Retired	8/30/2023 7:15 AM
15	Independent Lived Experience cobsultant	8/30/2023 5:34 AM
16	Peer worker in mental health	8/29/2023 10:23 PM
17	Psychologist/business owner	8/29/2023 8:57 PM
18	Carer	8/29/2023 8:49 PM
19	Health Consumer Rep, National and District	8/29/2023 5:34 PM
20	AOD manager	8/29/2023 3:46 PM
21	Learning and Development	8/29/2023 2:00 PM
22	disability support pension, have previously worked as a teacher and professional writer/editor	8/29/2023 1:08 PM
23	Financial Counsellor	8/29/2023 11:55 AM
24	Peer worker and a equine assisted psychotherapist	8/29/2023 11:53 AM
25	The Equine Psychotherapy Institute - my role is assessment and student support	8/29/2023 11:29 AM
26	Government	8/29/2023 10:11 AM
27	Lived Experience researcher and facilitator	8/29/2023 9:54 AM
28	Public Health Researcher	8/29/2023 9:17 AM
29	EAL Wilkydoo Equine Connection	8/29/2023 8:50 AM
30	Marketing Officer - Lived Experience Australia	8/29/2023 8:08 AM
31	Researcher	8/29/2023 7:56 AM

00	Celf annula and magnetal handlike assures	0/00/0000 40:05 DM
32	Self employed mental health nurse  Mental health, wellbeing, health - self employed	8/28/2023 10:25 PM 8/28/2023 9:29 PM
34	Retired	8/28/2023 6:33 PM
35	Chairperson National PHN Mental Health Lived Experience Engagement Network (MHLEEN)	8/28/2023 6:26 PM
36	Chair and Executive Director, Lived Experience Australia Ltd	8/28/2023 5:30 PM
37	Social worker	8/28/2023 5:16 PM
38	Well being worker	8/28/2023 5:09 PM
39	Retired	8/28/2023 5:04 PM
40	Activity Coordinator	8/28/2023 4:19 PM
41	Retired	8/28/2023 4:04 PM
42	Cafe owner	8/28/2023 3:38 PM
43	N/a. Unpaid carer	8/28/2023 3:37 PM
44	Mental Health Support Worker	8/28/2023 2:41 PM
45	Peer Worker	8/28/2023 11:49 AM
46	Director in Community Services	8/28/2023 11:23 AM
47	Senior Research Fellow of Lived Experience	8/28/2023 10:51 AM
48	Compliance officer	8/28/2023 10:04 AM
49	Senior Research Fellow, The University of Melbourne	8/28/2023 9:04 AM
50	Senior Peer Support Worker - headspace	8/28/2023 8:47 AM
51	Educator	8/28/2023 8:39 AM
52	Lived experience researcher	8/28/2023 8:25 AM
53	Mental Health Support Worker	8/28/2023 8:13 AM
54	CEO of Mental Health Consumer run organisation and Mental health advocate	8/28/2023 7:21 AM
55	Lived experience advocate	8/28/2023 5:50 AM
56	CEO of VMIAC (Victorian Mental Illness Awareness Council)	8/27/2023 10:18 PM
57	Manager	8/27/2023 10:12 PM
58	Metallurgist	8/27/2023 9:12 PM
59	Aged care assesdor	8/27/2023 6:16 PM
60	Studying for peer work	8/27/2023 6:08 PM
61	Case Manager	8/27/2023 5:40 PM
62	COTA NT	8/27/2023 5:38 PM
63	Trainer and Assessor	8/27/2023 4:40 PM
64	Scaffolder Darwin LNG	8/27/2023 4:39 PM
65	Registered Nurse	8/27/2023 4:25 PM
66	Pharmacist	8/27/2023 4:18 PM
67	Lived Experience Research Scientist	8/27/2023 4:16 PM
68	0835	8/27/2023 3:53 PM
69	Mental health nurse (ret.) Equine Assisted Learning Practioner	8/27/2023 3:44 PM
70	Fast food worker	8/27/2023 3:09 PM
71	CEO	8/27/2023 2:28 PM
72	Psychosocial Recovery Coach	8/27/2023 2:15 PM

73	Lived Experience Workforce Manager	8/27/2023 7:39 AM
74	General Manager	8/26/2023 11:18 PM
75	General Manager Medium Corporation	8/26/2023 11:17 PM
76	Family Reunification & Preservation Practitioner	8/26/2023 8:50 PM
77	Community work	8/26/2023 6:55 PM
78	Support worker	8/26/2023 4:58 PM
79	Customer Service	8/26/2023 4:23 PM
80	Mental health peer support worker	8/26/2023 3:36 PM
81	Community development coordinator	8/26/2023 2:02 PM
82	Nurse	8/26/2023 1:06 PM
83	Counsellor self employed	8/26/2023 1:04 PM
84	storeman department of health	8/26/2023 12:45 PM
85	Retired	8/26/2023 11:12 AM
86	Disability Pensioner due to 2 Traumatic Car Accidents	8/26/2023 10:49 AM
87	Retired	8/26/2023 10:44 AM
88	Peer Support	8/26/2023 10:42 AM
89	SWOPNT @ NTAHC	8/26/2023 10:39 AM
90	Auditor	8/26/2023 9:49 AM
91	Educationalist	8/26/2023 9:48 AM
92	Queensland lived experience workforce network	8/26/2023 9:26 AM
93	Project manager	8/26/2023 9:17 AM
94	NGO / small business	8/26/2023 9:08 AM
95	Cleaner	8/26/2023 8:51 AM
96	Currently unemployed	8/26/2023 8:42 AM
97	Education	8/26/2023 8:37 AM
98	Nurse - RDH	8/26/2023 8:30 AM
99	Retired community mental health and family services practitioner	8/26/2023 8:18 AM
100	Senior Carer Consultant in Lived Experience at Grampians Health	8/26/2023 7:37 AM
101	NT Health	8/26/2023 7:28 AM
102	Special Education Support Officer	8/26/2023 7:27 AM
103	General Manager of Inclusion at Flourish Australia and Founder of Vision In Mind	8/26/2023 1:00 AM
104	Public servant	8/25/2023 11:42 PM
105	Lived Experience Lead/Facilitator	8/25/2023 9:40 PM
106	Deputy Commissioner (Lived Experience) Menta Health Commission of NSW	8/25/2023 8:08 PM
107	Child and Family Partner Advisor	8/25/2023 8:07 PM
108	Peer support worker	8/25/2023 6:44 PM
109	Mental Health Recovery Work	8/25/2023 4:07 PM

Optional: Check this box if you support the NT Lived Experience Network to be recognized and supported by the NT Government as a NT-wide representative body.





* RESPONSES	
%COCOOL	137



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30 August 2023

Executive Director

Mental Health Alcohol and other Drugs Branch – NT Health
PO Box 40596

Casuarina NT 0811

Dear Cecilia

Thank you for the opportunity to provide comment on the NT Lived Experience Framework. The document provides a broad policy position, and we would like to make some suggestions about where it could be extended or strengthened to ensure that its ambitions are realised. In doing so I am drawing on my personal experience of working in the field of mental health and Lived Experience advocacy for over thirty years, most recently with Mind Australia.

One of the early lessons from this work is the recognition that power imbalances are not shifted by good intentions and isolated consumer voices on advisory groups. Sadly this is the proposed direction in the document.

A lived experience framework should not only be about service improvement, but also about promotion and protection of human rights. The interests of providers and users of services are not always the same and that is why a lived experience framework is so important. The NT has lagged the rest of the country for years in supporting lived experience contributions to the sector with no funding to support peer work, capacity building and very limited consumer consultant roles. It is deeply disappointing that this document does not provide a real commitment to ensuring an active consumer voice.

In section 10 the document provides a rationale for not funding a lived experience organisation to build and offer a community voice. Essentially it says that because it would be difficult to represent all voices, then no voice will be funded. The NT is no different to Queensland or WA where there has been consumer organisations for decades.

These organisations don't pretend to speak for all consumers, but provide a platform to support the consumer voice to be heard, and they don't exist purely to advise government. They are about capacity building, trusted consultation, networking and as demonstrated in other states they build the level of skill and knowledge and over time come to be key players in public policy. They develop methods to broader the richness and depth of their input. This is not achieved by isolated experiences of paid participation with no structural power, which is the direction in the draft Framework document. The rationale does not hold up to scrutiny or reflect the commitments articulated by the National Mental Health Commission.

The suggestion that the Local Decision Making Framework will be an avenue for the mental health consumer voices is disingenuous, as is saying there are multiple networks in the Top End that do the job. All of these exist on the smell of an oily rag, if they have any funding at all, and are mainly focused on suicide prevention. Whilst they do a mighty job in raising community awareness this is by no means the same as providing a platform where people with a lived experience can share concerns, build their skills and strengthen their voice to contribute to broader human rights, mental health policy, system reform, decision-making and service development. As you would be aware suicide prevention is only a small aspect of mental health policy and practice.

The Framework is an opportunity to demonstrate that NT shares a commitment to the human rights of people with a mental illness, and that it knows what it takes to support and build a vigorous voice for people with a lived experience. At this stage it looks like that opportunity has been missed. A commitment to active fostering of consumer voice drawing on best practice should be the minimum commitment. People with lived experience deserve more than the status quo.

I hope these comments can be taken into consideration and that a far more aspirational and contemporary commitment can be articulated in the Framework.

Kind regards,

Merrilee Cox

General Manager

Meriles Cex.



Professor James Smith BAppSc Hons, BEd, GCPH, PhD, FAHPA Matthew Flinders Professor (Health & Social Equity) Deputy Dean Rural and Remote Health NT

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29th August 2023

Mental Health Alcohol and Other Drugs Branch NT Department of Health PO Box 40596 Casuarina NT 0811

Re: Response to the NT Lived Experience Engagement Framework

Dear Mental Health and Alcohol and Other Drugs Branch

Thank you for the opportunity to comment on the draft NT Lived Experience Engagement Framework.

Flinders University is a hub for innovative health and medical research, education, and workforce development in the Northern Territory. Nested within the College of Medicine and Public Health, Flinders Rural and Remote Health has served the NT community in this way for the past 25 years, and has campuses based in Nhulunbuy, Darwin, Katherine, Tennant Creek, and Alice Springs. All activities are driven by our values which focus on both the short-term and long-term needs of the NT community. Flinders research footprint in the NT continues to grow and sits at the nexus of rural and remote health, and Aboriginal and Torres Strait Islander health and wellbeing. This includes multiple researchers with an explicit interest in mental health, and social and emotional wellbeing. Importantly, this includes two Senior Research Fellow roles focused exclusively on understanding the lived experiences of people with mental health, and alcohol and other drugs, concerns.

While it is promising to see that the NT Department of Health has developed a draft *Lived Experience Framework*, there has clearly been a lack of engagement with the lived experience community in the NT throughout its development. In preparing the draft *Lived Experience Framework*, the Mental Health and Alcohol and Other Drugs (MHAOD) Branch has also ignored the growing body of local research and evaluation evidence that has emerged over the past four years specifically relating to the lived experiences of mental health in the NT, including evidence relating to peer education, recovery, and preferred support mechanisms. Much of this evidence has been generated by Flinders researchers that have worked collaboratively with the NT Lived Experience Network (NTLEN) and other local organisations and peak bodies, including the NT Mental Health Coalition, TeamHEALTH, Top End Mental Health Consumer Organisation, Anglicare, the Alcohol and Drug Foundation, and NTPHN. Such evidence has been published in multiple technical reports and peer-reviewed journals; and presented at numerous territory and national mental health-related conferences. Most of these are readily accessible online (see Appendix A) and could help strengthen the focus of, or significantly reframe, the draft *Lived Experience Engagement Framework*. Flinders would be happy to present its research and emerging findings to the MHAOD Branch and other interested organisations and



peak bodies, if there is genuine interest in responding to the lived experiences of people with mental health concerns in the NT.

To help summarise, the findings of our above-mentioned research show that:

- Peer education and recovery programs that the NTLEN has delivered in Darwin, Palmerston, and more recently in Katherine and Alice Springs, have had significant impacts on the recovery and wellbeing of participants.
- The need and demand for peer support in the local community is significant and should be guided by the lived experience of individuals and carers.
- NTLEN has the capacity and ability to connect with, create trust with, and advocate on behalf
  of, a culturally diverse and geographically dispersed population of people with lived
  experience across the NT.

Recommendations drawn from our research and evaluation of lived experiences of mental health in the NT have outlined that:

- 1. Further investment in peer-led mental health and AOD recovery programs for sustainability, expansion and scalability across the NT is required. There is potential to adapt these programs through co-design processes for specific cohorts in various settings.
- 2. Building the capacity of a local peer workforce with relevant expertise and lived experience is important; and should utilise the stepped/supported vocational pathway developed by NTLEN.
- 3. Greater awareness about personal treatment options and peer-recovery planning strategies has been noted among mental health consumers that have participated in peer recovery programs and supported the development of contextually relevant peer-recovery models.
- 4. Ongoing planning and implementation of these locally co-designed peer-led programs is required to support the mental health recovery of individuals.
- 5. Persistent advocacy to sustain these programs is required sustain momentum and improve mental health outcomes of the NT community.
- 6. Locally delivered programs have supported the promotion and facilitation of broader peer connections at local, regional, territory-wide and national levels.
- 7. A permanent 'place' for peer support programs that is easily accessible and safe for participants is required and could take the form of a local Recovery College (or similar).
- 8. There is an opportunity to re-develop programs to align with an entry pathway to accredited vocational education and training.
- 9. Emerging peer-led psychosocial education and support programs in the NT are showing early signs of success.
- 10. Investment in collaborations between researchers and mental health consumers can increase consumer participation in applied research and evaluation activities.

Flinders University is a formal institutional partner with the ALIVE National Centre for Mental Health Research Translation (<a href="https://alivenetwork.com.au">https://alivenetwork.com.au</a>). This is a national research network privileging the voices of those with lived experience of mental health concerns. NTLEN has also been supporting governance of ALIVE since its inception. In March 2023, Flinders co-hosted the ALIVE annual symposium in Darwin. This provided an opportunity to show-case local lived experiences of mental health in the NT, including findings from many of the abovementioned research and evaluation projects (see Appendix A).

The NT is currently the only jurisdiction in Australia that does not have government funded lived experience peak body that represents the collective voice of people with lived experience of mental health and illness. As such, the mental health system has suffered. It is well documented that the NT has particularly high rates of mental illness, suicide ideation, and suicide, particularly among



Aboriginal and Torres Strait Islander people. This needs to change. Investment in a lived experience peak body is well overdue and could help change this narrative. Similarly, more substantial investment in local mental health research is also required.

Throughout 2022-2023 Flinders Rural and Remote Health NT has established two Senior Research Fellow positions specifically tasked with examining the lived experiences of mental health consumers in the NT. Dr Noemi Tari-Keresztes and Dr Himanshu Gupta have both been appointed to these roles, reflective of their genuine and close professional allyship with local lived experience peer advocates since 2019. In addition, Associate Professor Kootsy Canuto has been leading a research project focused on the social and emotional wellbeing of Aboriginal and Torres Strait Islander males in SA and the NT that is funded through the Medical Research Future Fund. Dr Oliver Black has been appointed as a Senior Lecturer - Mental Health and is leading a project focused on Aboriginal and Torres Strait Islander youth stepped-care in East Arnhem that is funded by the Australian Government. Professor James Smith has been leading a project focused on the adaptation and implementation of an online social and emotional wellbeing education and support program for young Aboriginal and Torres Strait Islander males that is funded by Movember. All of these projects have been underpinned by co-design processes engaging people with lived experience of mental health and/or social and emotional wellbeing concerns. We welcome the NT Government to make a similar investment in research and evaluation of this nature, and to work in partnership with our team.

Flinders recognises the importance of developing a *Lived Experience Engagement Framework* in the NT, but also considers a lived experience peak body (with a collective vision) should be adequately funded to oversee its development and implementation. Key tasks should include:

- Building the capability of the lived experience community to participate in systemic advocacy.
- Establishing networks within and across jurisdictions to collate and elevate issues of concern and to generate tangible solutions.
- Champion the experiences and perspectives of the people with lived experience.
- Contribute to relevant local and national-level decision-making.

The NT Government should recognise and support a lived experience representative body in the NT akin to all other state and territory governments across Australia. Flinders considers that the NT Lived Experience Network is well positioned to take on this role.

Yours sincerely

**Prof James Smith** 

Cc: Ms Noelene Armstrong, NT Lived Experience Network



# Appendix A – Selected publications and presentations relating to lived experience mental health research and evaluations in the NT from 2019-2023

#### Publications:

- Tari-Keresztes, N., Gupta, H., Armstrong, N., Smith, J., Endemann, SA. (2023). Evaluation of the After Hours 'Recovery Together' Program. Darwin, NT, Flinders University <a href="https://doi.org/10.25957/g2yd-xt11">https://doi.org/10.25957/g2yd-xt11</a>
- Tari-Keresztes, N., Armstrong, N., Smith, J., Gupta, H., Goding, S., Endermann, SA, Mulholland, K. (2022). Supporting family members' and friends' individual recovery with a locally co-designed peer-led recovery program in Darwin. Alcohol and Drug Foundation <a href="https://www.flinders.edu.au/content/dam/documents/research/flinders-nt/supporting-family-members-friends-individual-recovery-report.pdf">https://www.flinders.edu.au/content/dam/documents/research/flinders-nt/supporting-family-members-friends-individual-recovery-report.pdf</a>
- Tari-Keresztes, N., Smith, J., Gupta, H., Aanundsen, D. (2022). Evaluation of the "Professionalising the NT Peer Workforce and expanding peer supports for Territorians who experience mental health challenges" project. Darwin, NT, Flinders University.
- Tari-Keresztes, N., Gupta, H. & Smith, J. (2022). *Evaluation of the Two Ways Mentoring Program*. Darwin: Menzies School of Health Research
- Tari-Keresztes, N., Smith, J. & Gupta, H., (2021). Follow-up Evaluation of the Peer-Led Education Pilot in Darwin. Darwin: Menzies School of Health Research <a href="https://www.menzies.edu.au/icms">https://www.menzies.edu.au/icms</a> docs/330899 Follow-up Evaluation of the Peer-Led Education Pilot in Darwin.pdf
- Tari-Keresztes, N., Christie, B., Gupta, H., Wallace, T., Stephens, D., Caton-Graham, P. & Smith, J. (2020). Evaluation of a Peer-Led Education Pilot for people with psychosocial support needs in Darwin, Northern Territory. Darwin, Menzies School of Health Research <a href="https://www.menzies.edu.au/icms docs/320338">https://www.menzies.edu.au/icms docs/320338</a> Evaluation of a Peer-Led Education Pilot for people with psychosocial support needs in Darwin Northern Territory.pdf
- Tari-Keresztes N, Armstrong N, Smith JA, Gupta H, Goding S, Endemann S-A. (2023). "You Don't Get That from Professionals": A Consumer-Led Peer Recovery Program for Families and Friends of Individuals with Alcohol and Other Drugs Use Issues in Darwin. *International Journal of Environmental Research and Public Health*. 20(8):5514. https://www.mdpi.com/1660-4601/20/8/5514
- Tari-Keresztes N, Girdler X, Gupta H, Clarke B, Christie B, Smith J, et al. (2022). 'Like a family in the end': Improving mental health Recovery skills through Peer-to-Peer communication in Darwin, Australia. *Health & Social Care in the Community*. 30 (6), e5336-5345 <a href="https://pubmed.ncbi.nlm.nih.gov/35949176/">https://pubmed.ncbi.nlm.nih.gov/35949176/</a>

#### Presentations:

- Tari-Keresztes, N., Armstrong, N., Smith, J., Gupta, H., Featherston, P. *Peer education and recovery in the Northern Territory,* TheMHS, Adelaide, Australia, 15-18 August 2023
- Armstrong, N., Tari-Keresztes, N., Bretherton, R., Smith, J., Gupta, H. *Pilot and Evaluation Recovery Together*, AADANT Conference, Darwin, Australia, 23-24 May 2023
- Tari-Keresztes, N. Armstrong, N., Smith, J., Gupta, H. The Circles of Support. AADANT Conference, Darwin, Australia, 23-24 May 2023
- Tari-Keresztes, N. Armstrong, N., Smith, J., Gupta, H., Featherston, P. The journey of the emerging peer initiatives in the NT. Preventive Health Conference, Adelaide, Australia, 02-04 May 2023
- Tari-Keresztes, N., Armstrong, N., Smith, J., Gupta, H., Goding, S., Endemann, SA. *The Circles of Support: "I wish I'd known...this a lot earlier in my life."* Australian & New Zealand Addiction Conference, Gold Coast, Australia, 26-28 April 2023



- Armstrong, N., Tari-Keresztes, N., Smith, J., Gupta, H., *Peer Programs in the NT*. ALIVE Annual Symposium, Darwin, Australia, 30-31 March 2023
- Tari-Keresztes, N., Armstrong, N., Smith, J., Gupta, H. Where are we now? Snapshot of the emerging Lived Experience projects in Darwin. 23rd International Mental Health Conference, Gold Coast, Australia, 5-7 September 2022
- Armstrong, N., Tari-Keresztes, N., Smith, J., Gupta, H. *The birthplace of the Northern Territory's first Lived Experience advocacy body: The Peer-Led Education Pilot.* 23rd International Mental Health Conference, Gold Coast, Australia, 5-7 September 2022
- Tari-Keresztes, N., Endermann, SA, Armstrong, N., Smith, J., Gupta, H., Goding, S., Mulholland, K.: Supporting family members' and friends' individual recovery with a locally codesigned peer-led recovery program in Darwin. Alcohol and Drug Foundation ISS Symposium, Melbourne, Australia, 9 June 2022
- Armstrong, N, Tari-Keresztes, N., Gupta, H., Smith, J., Harris, V. Project Overview: Peer-Led Education Pilot, AADANT Peer Workers Professional Development, Darwin, Australia, 22 February 2022
- Tari-Keresztes, N., Armstrong, N., Gupta, H., Smith, J., Harris, V. *The experience of recovery for participants in the Darwin Peer-Led Education Pilot (PLEP)*, Menzies Research Ideas Forum, Building the evidence-base for prevention of suicide and self-harm, Darwin, Australia, 16 June 2021
- Armstrong, N., Tari-Keresztes, N., Girdler, X., Gupta, H., Smith, J., Harris, V., Christie, B., Clarke, B.: Personal recovery and peer support in mental health and alcohol and other drugs context, AADANT Conference: Diversify and Adapt, Darwin, Australia, 18-19 May 2021
- Armstrong, N., Tari-Keresztes, N., Smith, J. & Harris, V. I was in a cage.....The cage door opened. Slowly... I now have a choice. To stay in the cage, in the dark. Or leave. And become the person I have always known I could be." NTPHN Webinar series about Recovery and Peer Support. 10 December 2020, Darwin.
- Gupta H, Tari-Keresztes N, Keys L. "It was relevant, useful and gave me tools; it created connection, changed my perspective and gave me HOPE": Participants' journey in the Peer-Led Education Pilot in Darwin (PLEP)", Menzies Tuesday Seminar, Darwin, Australia, 17 November 2020



NT Lived Experience Network Darwin, Northern Territory

Care of Noelene Armstrong e: <u>contact@livedexperiencent.net</u> m: 0438 022 032

28 August 2023

Dear NT Lived Experience Network,

# Re: Support Letter for the NT Lived Experience Network's response to the draft NT Lived Experience Framework

As CEO of Bipolar Australia, I have reviewed your response dated the 25<sup>th</sup> of August 2023 to the draft NT Lived Experience Framework. On behalf of Bipolar Australia, I would like to formally provide our organisation's support to your response.

Bipolar Australia was founded in 2014, is a Lived Experience founded and led national not for profit organisation, supporting everyone affected by Bipolar Disorder including people with Bipolar conditions, their family, friend and kin carers, as well as promoting positive understanding of Bipolar disorders for service providers and health workforce.

Bipolar Australia raises community awareness about Bipolar Disorders, advocacy for elimination of stigma and discrimination and provide evidence-based education programs, information and resources. We encourage formation of Bipolar Support groups and are involved in national research about Bipolar conditions.

Bipolar Australia recognises the imperative to support the establishment of strong and collective lived experience advocacy bodies to

- Build the capability of their community to participate in systemic advocacy;
- Establish networks across jurisdictions to collate and elevate issues of concern and solutions;
- Champion the experiences and perspectives of the people they represent; and
- Contribute to local and national level decision making.

We believe the NT Government, should recognise and support a lived experience representative body in the NT in the same way that all other Australian state and territory governments have done.

We call on the NT Government to recognise and support the NT Lived Experience Network to establish themselves as the NT lived experience representative body.

Sincerely
Eileen McDonald
Chief Executive Officer Bipolar Australia
eileen.mcdonald@bipolaraustralia.org.au
+61 438 221 751





### Top End Mental Health Consumer Organisation Incorporated

PO Box 391
Palmerston NT 0801
3 Maluka Drive
PALMERSTON NT 0830
Mob: 0429 082 781
exec@temhco.com.au

NT Lived Experience Network Darwin, Northern Territory

Care of Noelene Armstrong
e: contact@livedexperiencent.net
m: 0438 022 032

28 August 2023

Dear NT Lived Experience Network,

Re: Support Letter for the NT Lived Experience Network's response to the draft NT Lived Experience Framework

As Chief Executive Officer of Top End Mental Health Consumers Organisation (TEMHCO) Inc., I have reviewed your response dated the 25<sup>th</sup> of August 2023 to the draft NT Lived Experience Framework. On behalf of TEMHCO I would like to formally provide our organisation's support to your response.

TEMHCO was founded in 1999 and provide people living with mental illness a drop-in centre where they can feel safe, build friendships, and receive the help and support they need. We encourage wellness and social inclusion within our community to promote and protect good mental health for all and treat people with the experience of mental distress fairly, positively and with respect. We aspire to continuously promote mental wellbeing to our members and to the wider community. We advocate for our members to help educate the wider community regarding breaking the stigma and shame placed on mental illness and are committed to achieving improved outcomes for people with a mental illness, their carers and their families. Our ultimate vision is to help our members live full and meaningful lives where they have the confidence to participate in society.

We recognise the imperative to support the establishment of strong and collective lived experience advocacy bodies to

- Build the capability of their community to participate in systemic advocacy;
- Establish networks across jurisdictions to collate and elevate issues of concern and solutions;
- Champion the experiences and perspectives of the people they represent; and
- Contribute to local and national level decision making.

We believe the NT Government, should recognise and support a lived experience representative body in the NT in the same way that all other state and territory governments have done.

We believe that the Northern Territory needs to have its own mental health peak body and not a range of smaller networks that is currently in operation as their voices are not always heard or supported. We believe that having one mental health lived experience representative body that can oversee and collaborate effectively with all the existing networks as a collective will ensure that we can stand united and that our voices will be heard.

Yours sincerely

8 Jag

Helen Day

Chief Executive Officer - TEMHCO



NT Lived Experience Network Darwin, Northern Territory

Care of Noelene Armstrong
e: contact@livedexperiencent.net
m: 0438 022 032

30th August 2023

Dear NT Lived Experience Network,

### Re: Support Letter for the NT Lived Experience Network's response to the draft NT Lived Experience Framework

As the Senior Peer Support Worker of headspace Darwin, I have reviewed your response dated the 25<sup>th</sup> of August 2023 to the draft NT Lived Experience Framework. On behalf of headspace Darwin and headspace Palmerston I would like to formally provide our organisation's support to your response.

headspace Darwin was founded in 2007 to help young people aged 12 to 25 with their mental health and wellbeing. We offer peer support services by designated lived experience staff, and place immense value on the role of lived experience in the mental health system to both provide services and drive positive change.

We recognize the imperative to support the establishment of strong and collective lived experience advocacy bodies to

- Build the capability of their community to participate in systemic advocacy;
- Establish networks across jurisdictions to collate and elevate issues of concern and solutions;
- Champion the experiences and perspectives of the people they represent; and
- Contribute to local and national level decision making.

We believe the NT Government, should recognise and support a lived experience representative body in the NT in the same way that all other state and territory governments have done.

We call on the NT Government to recognise and support the NT Lived Experience Network to establish themselves as the NT lived experience representative body.

Yours sincerely,

Leila Heinrich Senior Peer Support Worker headspace Darwin



P.O. BOX 1029 Nhulunbuy NT 0880 M: 0498 798 008

E: topcornerpsychology@gmail.com

Thursday 30 August, 2023 [30/08/2023]

NT Lived Experience Network Darwin, Northern Territory

Care of Noelene Armstrong e: contact@livedexperiencent.net

m: 0438 022 032

Dear NT Lived Experience Network,

# Re: Support Letter for the NT Lived Experience Network's response to the draft NT Lived Experience Framework

As Psychologist and Owner of Top Corner Psychology, I have reviewed your response dated the 25th of August, 2023 to the draft NT Lived Experience Framework. On behalf of Top Corner Psychology, I would like to formally provide our organization's support to your response.

Top Corner Psychology (TCP) was founded in 2023 to provide psychological intervention and assessment to vulnerable individuals, couples and families in Arnhem Land. After working in Arnhem Land, NT, for several years, I saw the need for better access to psychological services for those living on country, and who were experiencing difficulty with access from a financial perspective. TCP endeavors to offer a service that is of the highest quality, to those who experience hardship, using both my professional experience but my lived experience in my service delivery. TCP's launch has opened up extensive opportunities for those who would normally be unable to obtain psychology appointments, giving individuals, couples and groups the access they deserve and require. In all my endeavors, I aim to ensure a positive change in my community, providing opportunities for growth and continued engagement.

We recognize the imperative to support the establishment of strong and collective lived experience advocacy bodies to:

- Build the capability of their community to participate in systemic advocacy;
- Establish networks across jurisdictions to collate and elevate issues of concern and
- solutions;
- Champion the experiences and perspectives of the people they represent; and



P.O. BOX 1029 Nhulunbuy NT 0880 M: 0498 798 008

E: topcornerpsychology@gmail.com

Contribute to local and national level decision making.

We believe the NT Government, should recognise and support a lived experience representative body in the NT in the same way that all other state and territory governments have done.

We call on the NT Government to recognise and support the NT Lived Experience Network to establish themselves as the NT lived experience representative body.

If you have any questions regarding the content of this letter, please do not hesitate to contact the practice via email (<a href="mailto:topcornerpsychology@gmail.com">topcornerpsychology@gmail.com</a>) or via telephone 0498798008.

Warm regards,

Tamika Galea

Owner/Psychologist

**Top Corner Psychology** 



NT Lived Experience Network Darwin, Northern Territory

Care of Noelene Armstrong
e: contact@livedexperiencent.net
m: 0438 022 032

27<sup>h</sup> August 2023

Dear NT Lived Experience Network,

# Re: Support Letter for the NT Lived Experience Network's response to the draft NT Lived Experience Framework

As Psychosocial Recovery Coach of NT Psychosocial Recovery and Support Services, I have reviewed your response dated the 25<sup>th</sup> of August 2023 to the draft NT Lived Experience Framework. On behalf of NT Psychosocial Recovery and Support Services, I would like to formally provide our organisation's support to your response.

Psychosocial Recovery and Support Services, established in 2021, is driven by a profound purpose - to champion the mental well-being and holistic recovery of individuals within the community. Our mission is to create a positive and lasting impact in the mental health sector through unwavering advocacy and the nurturing of robust support networks. We are committed to offering person-centred support that empowers and motivates individuals to strive towards their unique goals, fostering an environment of understanding, acceptance, and growth.

#### Vision:

Our vision at NT psychosocial recovery and support services is to be at the forefront of providing exceptional support services that enable individuals with disabilities to lead lives of increased independence and fulfilment within the community. We aspire to create a world where every individual unique strengths are celebrated and where they can thrive within an inclusive society.

We envision a society where mental health challenges are met with empathy and comprehensive support, allowing each person to harness their potential, overcome obstacles, and reach their personal aspiration's full stop by offering high-quality services and personalised assistance. We aim to facilitate a journey of recovery that transcends limitations, empowers self-discovery, and fosters lasting connections.

Through our dedication, innovation, and unwavering commitment to providing mental well-being, we strive to build a future where every person's journey is marked by resilience,

growth, and a strong sense of belonging. Our vision is the driving force behind all that we do, and it guides us in creating a better, more inclusive world for individuals with disabilities.

We recognise the imperative to support the establishment of strong and collective lived experience advocacy bodies to

- Build the capability of their community to participate in systemic advocacy;
- Establish networks across jurisdictions to collate and elevate issues of concern and solutions:
- Champion the experiences and perspectives of the people they represent; and
- Contribute to local and national level decision-making.

We believe the NT Government should recognise and support a lived experience representative body in the NT in the same way that all other state and territory governments have done.

We call on the NT Government to recognise and support the NT Lived Experience Network to establish themselves as the NT Lived Experience representative body.

Your Charles

Billie-Jean Maiden



NT Lived Experience Network Darwin, Northern Territory

Care of Noelene Armstrong

e: contact@livedexperiencent.net

m: 0438 022 032

28 August 2023

Dear NT Lived Experience Network,

# Re: Support Letter for the NT Lived Experience Network's response to the draft NT Lived Experience Framework

As Executive Officer of Red Flag Canberra Inc. I have reviewed your response dated the 25<sup>th</sup> of August 2023 to the draft NT Lived Experience Framework. On behalf of Red Flag Canberra Inc. I would like to formally provide our organisation's support to your response.

Red Flag Canberra Inc. was founded in 2018 as a mental health advocacy organisation demanding mental health action and recognition of the lived experience voice.

We recognize the imperative to support the establishment of strong and collective lived experience advocacy bodies to

- Build the capability of their community to participate in systemic advocacy;
- Establish networks across jurisdictions to collate and elevate issues of concern and solutions;
- Champion the experiences and perspectives of the people they represent; and
- Contribute to local and national level decision making.

We believe the NT Government, should recognise and support a lived experience representative body in the NT in the same way that all other state and territory governments have done.

We call on the NT Government to recognise and support the NT Lived Experience Network to establish themselves as the NT lived experience representative body.

Yours sincerely

Jane Grace Executive Officer

Red Flag Canberra Inc. listentoconsumers@gmail.com 0434568226



Copy of the submission to the Lived Experience Framework provided by Alice Springs Lived Experience Advocate, Alison Cunynghame, to support the NT Lived Experience Network's submission.

First thoughts: Document is not accessible. Is long, repetitive, vague and information is not in appropriate order. For example, to demonstrate genuine respect, acknowledgements should preface the document.

Is also not clear on what this framework is for? Is it for lived experience workforce or lived experience engagement? And if so in what capacity? It's quite limited and non-committal in its goals. It is not clear.

For example, LEWP Lived Experience Workforce Program states.

"A mental health Lived Experience /Peer worker is someone who is employed in a role that requires them to have lived experience of mental health challenges and periods of healing /recovery. This can be either personal lived experience or as a carer /family of someone who experiences mental health challenges"

This document itself fails to clearly define what the intention is, as well as draw on already existing frameworks such as LEWP. What is the reason that this document isn't acknowledging that strong bodies of lived experience frameworks already exist? Can it reference and expand on already existing work while seeking to overcome barriers unique to the NT?

Upon reading it seems that the author/authors themselves are unclear on definitions and polices. Overall, intention of this document isn't made clear. Points that it addresses are not expanded on, such as "sustainability in the workforce" It emphasises about including lived experience, but again fails to expand on this.

Many service users and lived experience advocates are prone to reading familiar terms of "collaboration" "inclusion" "acknowledging lived experience" within these kinds of documents.

Without meaningful application, there is no accountability, and consequently, there is no meaningful progress. Because of this, attempts of developing a framework such as this, does come across as disingenuous and more about appearing stakeholders.

It is evident that this document, aside from being tokenistic, has not consulted with lived experience, which contradicts its purpose. It has not been developed with genuine lived experience workforce input. An example of this is the inaccessibility of language, and definitions being unclear and outdated.

Who was invited to contribute this framework? As it seems to have very limited input, and again contradicts the value of meaningful collaboration. Even on the NT website descriptions about the purpose of the framework are vague and unclear.

The authors state it as being a guide that will be implemented, but the document itself seems to be very vague. Due to this it can be interpreted in many ways, which could result in harm, as there doesn't seem to be anything to encourage service providers to change current practices.

Again, definitions are not in line with current social climate, are excessively worded, and again there is confusion as the reason why they are stated in the first place since they are not referenced again with the document. Glossary should be at the end of a document. It should also be assumed knowledge by service providers and interested parties.

If this document is meant to be in reference to developing a lived experience workforce (again unsure due to lack of clarity) why are relevant terms such as 'trauma informed" "peer worker" "recovery" not included?

Existing frameworks, such as the LEWP framework has a strong organizational action plan that ensures polices will be in place for LE safety and sustainability.

It does not appear that other existing frameworks have been referenced in the development of this framework.

Within the key messages it is stated that staff will have a clear understanding of expectations, roles, and responsibilities, when undertaking engagement activities and will be supported accordingly. Again, this is non-committal and not encouraging accountability for organizations.

Another key message is "where possible LE will be involved from the outset".

However, it does not mention it as a requirement and undermines the fact that Lived experience can also hold professional qualifications.

"Meaningful participation" should also have the inclusion of fair credit and compensation for lived experience expertise.

Quite often LE are invited for narrow participation, in the development of peer frameworks that directly affect service users, yet the integrity of knowledge and insight is then given to organisations without any meaningful inclusion such as follow up. The weight of lived experience knowledge is overruled by professional opinion.

Though it's stated as a "broad adaptive document" under 6. Purpose, it seems to only outline clarification of terms, not practices.

There is no way to see how this document will be implemented, such as KPI for peer hours delivered, and lived experience workforce safety. Unfortunately, the document in its current state of being quite vague and unclear, there will be no way to determine its effectiveness.

Under 7 Policy Context, it is stated that NT Health is "committed to working with people with lived experience" but again doesn't offer any parameters on workforce goals, or strategies. Due to this, it again it comes across as disingenuous and appearing rather than quantifiable. It is encouraging better practice without any clear goals for implantation.

Many of the statements made within this document comes across as "word salad." Language used is consistently vague, and excessively worded, making it inaccessible for many, which contradicts its many statements of inclusion, and meaningful engagement.

On page 18, with the table of enablers and solutions it finally states the need of using plain English, which is ironic considering throughout the document information is lengthy and difficult to decipher.

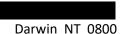
Also there seems to an excessive list of references, yet the confusion is that the supposed amount of research in developing this document is not reflected in the clarity of this framework. It does come across as though these references were simply complied to professionalise rather than inform the document.

In the Policy context, where it talks about the 4 key areas of promotion, there is no clear outline of what this framework is intended to underpin in the future such as planning the future mental health workforce, lived experience workforce development, and organisational LE workforce development action planning, (assuming this is the practical implantation of this framework.)

Overall, reading through this framework in its current state, it leaves me concerned for its implementation for the above reasons. It does not feel like a structured, usable document in its current state.

I would like to see clear applications of this document, with improved clarity and more accessible English throughout, to increase inclusion of Lived Experience input.

It is also disappointing to find that this feedback cannot be submitted anonymously because that this will also reduce participation and constructive criticism.



NT Lived Experience Network Darwin, Northern Territory Care of Noelene Armstrong <u>contact@livedexperiencent.net</u> 0438022032

27 August 2023

Dear NT Lived Experience Network

# Re: Support Letter for the NT Lived Experience Network's response to the draft NT Lived Experience Framework

As a person with extensive experience of the Northern Territory Mental Health sector, in both a personal and professional capacity, I have reviewed your response dated 25 August 2023 to the draft NT Lived Experience Framework. I would like to formally provide my support to your response.

I recognize the imperative to support the establishment of strong and collective lived experience advocacy bodies to:

- Build the capability of their community to participate in systemic advocacy,
- Establish networks across jurisdictions to collate and elevate issues of concern and solutions,
- Champion the experiences and perspectives of the people they represent,
- Contribute to local and national level decision making; and
- Ensure that Recovery oriented practices are genuinely adhered to by all practitioners within the sector.

I believe the NT Government should recognize and support a lived experience representative body in the NT in the same way that all other state and territory governments have done.

I call on the NT Government to recognize and support the Lived Experience Network to establish themselves as the NT Lived Experience representative body.

Yours sincerely

Chris Kuhl

NORTHERN TERRITORY LIVED EXPERIENCE NETWORK

NT Lived Experience Network Darwin, Northern Territory

Care of Noelene Armstrong
e: contact@livedexperiencent.net
m: 0438 022 032

25/08/2023

Dear NT Lived Experience Network,

### Re: Support Letter for the NT Lived Experience Network's response to the draft NT Lived Experience Framework

Greetings, my name is Sam, I am a Senior Practice Lead - certified peer support worker across multiple Mental Health organisations across the Northern Territory and abroad, designing/codesigning and facilitating Peer themed workshops, as well as providing one on one peer support, policy consultation and systemic review and advocacy. I have reviewed your response dated the 25<sup>th</sup> of August 2023 to the draft NT Lived Experience Framework, and as a highly experienced professional with a deep understanding of mental health and addiction issues, backed by personal lived experience, I feel I am well positioned to propose some amendments.

I'd like to share some of the concerns that my lived experience peers and I (Some of the most vulnerable people in the country, if not the world) share around the lack of consultation by our governments, with our community.

Recently, The Mental Health Alcohol and other Drugs Branch of the NT government has diligently prepared a statement of framework for lived experience largely taken straight from the National Mental Health Commissions existing guidelines. The branch has taken the first small step using wonderful buzz words like co development, partnerships and consultation.

The concerns, for me, arise upon the realization that this framework is being prepared by the same department who recently drew a line through the funding of Grow Mental health NT, a lived experience community that has served the Northern Territory for the past 42 years. Without any consultation with the management team from Grow or the Lived experience volunteer workers. This occurring mere months before drafting the framework, I can't help but feel sceptical around the level of inclusion pledged here.

In fact, it would appear that the key measures proposed in the draft are not being applied to this very process of consultation.

I implore the relevant Branch management team to consider what is being proposed carefully, bearing in mind the hundreds of vulnerable people and their families are detrimentally affected by such ill-considered decisions, and they all vote.

Furthermore, point 10 in the draft, is limiting the influence and participation of lived experience organisations in the NTs Local Decision-Making framework. It appears as though the MHAOD branch shall have the ability to choose who participates in regard to each decision-making activity. This would seem to rather defeat the purpose and intention of the overall framework and Point 10 ought to be removed. Ideally, an NT lived experience representative body should be included. A Lived experience peak body, with existing connections with all NT Mental Health services using lived experience, and the knowledge of what decisions will affect individual services should be employed. A simple, effective solution that is already afforded to our interstate colleagues. The notion that this could not be achieved due to the NTs diverse population is not a viable explanation given the MHAOD branches recent track record of excluding Lived experience communities directly impacted by their decisions.

In short, I call for the removal of point 10 and the inclusion of a Peak body to ensure the true intention, purpose and key messages are met. I fully support NTLEN in the following statement and urge you to consider these amendments and proposals intently.

We recognize the imperative need to support the establishment of strong and collective lived experience advocacy bodies to

- Build the capability of their community to participate in systemic advocacy.
- Establish networks across jurisdictions to collate and elevate issues of concern and solutions.
- Champion the experiences and perspectives of the people they represent; and
- Contribute to local and national level decision making.

We believe the NT Government, should recognise and support a lived experience representative body in the NT in the same way that all other state and territory governments have done.

We call on the NT Government to recognise and support the NT Lived Experience Network to establish themselves as the NT lived experience representative body.

Yours sincerely

Sam Goding



The Northern Territory Lived Experience Network (NTLEN) Darwin, Northern Territory

C/O Noelene Armstrong

e: contact@livedexperiencent.net

m: 0438 022 032

August 30, 2023

Dear NTLEN,

# Re: Support Letter for the NT Lived Experience Network's response to the NT Department of Health draft NT Lived Experience Framework

As Senior Research Fellows (Lived Experience), we have reviewed your response dated August 25, 2023, to the draft NT Lived Experience Framework. We would like to formally provide our individual support to your response.

We have been working in the lived experience research space in the NT since 2019 and have been involved as external evaluators for various local projects relating to personal recovery, community mental health, alcohol and other drug use (AOD), and gambling among people with diverse lived experience of mental ill-health, substance use and related challenges.

Peer work, peer education, and lived experience research have only emerged in the last few years in the NT, starting with the Peer-Led Education Pilot (PLEP) project and the NTLEN foundation. NT is the only jurisdiction in Australia that does not have an independent statewide lived experience peak body that represents the collective voice of people with lived experience, the local lived experience advocates, and researchers. Therefore, it is even more significant to foster connections with other lived experience experts on a local and national level and participate in relevant discussions, training, and collaborative opportunities. Thus, we developed a strong allyship with the NTLEN during the past few years. This collaboration allowed both parties to learn from each other and grow. This genuine relationship and mutual learning helped us, as researchers, learn how to engage with people with lived experiences genuinely. In collaboration with the NTLEN, through co-design processes, we also developed approaches to make our research proposals informed by people with lived experience and our research design, tools, and instruments recovery-oriented and strengths-based. From external evaluators, we have become co-creators of multiple grant proposals, academic publications, and conference presentations with people with lived experience, such as Ms Noelene Armstrong, Senior peer worker and advocate, and other lived experience representatives from the NTLEN (refer to Appendix A).

Most of our work is accessible online, and it is seriously concerning that the Mental Health and Alcohol and Other Drugs (MHAOD) Branch completely ignored the local lived experience evidence base that we built between 2019 and 2023. We believe the experience we gained and the evidence base we built could be a significant element in informing the development of the NT Lived Experience Framework. We know from our studies that (1) involving people with lived experience in research and decision-making is crucial, (2) NTLEN does have the capacity and ability to connect with, create trust with and advocate on behalf of the culturally diverse and geographically dispersed population of people with lived experience from across the NT, (3) NTLEN's peer programs delivered in Darwin, Palmerston, and recently in Katherine and Alice Springs have profound positive impacts on participants' recovery and wellbeing, and (4) the need and demand for ongoing peer support programs in the local community is enormous.

Thus, we recognise the imperative to support the establishment of strong and collective lived experience advocacy bodies to:

- Build the capability of their community to participate in systemic advocacy;
- Establish networks across jurisdictions to collate and elevate issues of concern and solutions:
- Champion the experiences and perspectives of the people they represent; and
- Contribute to local and national-level decision-making.

We believe the NT Government would recognise and support a lived experience representative body in the NT in the same way all other state and territory governments have done.

We call on the NT Government to recognise and support the NT Lived Experience Network to establish itself as the NT Lived Experience representative body.

Yours sincerely

Dr Noemi Tari-Keresztes

Or Veri Toa Kente

Dr Himanshu Gupta

Appendix A: Publications and presentations

#### Publications:

- Tari-Keresztes, N., Gupta, H., Armstrong, N., Smith, J., Endemann, SA. (2023).
   Evaluation of the After Hours 'Recovery Together' Program. Darwin, NT, Flinders University <a href="https://doi.org/10.25957/g2yd-xt11">https://doi.org/10.25957/g2yd-xt11</a>
- Tari-Keresztes, N., Armstrong, N., Smith, J., Gupta, H., Goding, S., Endermann, SA, Mulholland, K. (2022). Supporting family members' and friends' individual recovery with a locally co-designed peer-led recovery program in Darwin, Alcohol and Drug Foundation <a href="https://www.flinders.edu.au/content/dam/documents/research/flinders-nt/supporting-family-members-friends-individual-recovery-report.pdf">https://www.flinders.edu.au/content/dam/documents/research/flinders-nt/supporting-family-members-friends-individual-recovery-report.pdf</a>
- Tari-Keresztes, N., Smith, J., Gupta, H., Aanundsen, D. (2022). Evaluation of the "Professionalising the NT Peer Workforce and expanding peer supports for Territorians who experience mental health challenges" project. Darwin, NT, Flinders University.
- Tari-Keresztes, N., Gupta, H. & Smith, J. (2022). Evaluation of the Two Ways Mentoring Program. Darwin: Menzies School of Health Research
- Tari-Keresztes, N., Smith, J. & Gupta, H., (2021): Follow-up Evaluation of the Peer-Led Education Pilot in Darwin. Darwin: Menzies School of Health Research <a href="https://www.menzies.edu.au/icms">https://www.menzies.edu.au/icms</a> docs/330899 Follow-up Evaluation of the Peer-Led Education Pilot in Darwin.pdf
- Tari-Keresztes, N., Christie, B., Gupta, H., Wallace, T., Stephens, D., Caton-Graham, P. & Smith, J. (2020) Evaluation of a Peer-Led Education Pilot for people with psychosocial support needs in Darwin, Northern Territory. Darwin, Menzies School of Health Research
   https://www.menzies.edu.au/icms\_docs/320338\_Evaluation\_of\_a\_Peer-Led\_Education\_Pilot\_for\_people\_with\_psychosocial\_support\_needs\_in\_Darwin\_Nort\_hern\_Territory.pdf
- Tari-Keresztes N, Armstrong N, Smith JA, Gupta H, Goding S, Endemann S-A. "You Don't Get That from Professionals": A Consumer-Led Peer Recovery Program for Families and Friends of Individuals with Alcohol and Other Drugs Use Issues in Darwin. International Journal of Environmental Research and Public Health. 2023;20(8):5514. <a href="https://www.mdpi.com/1660-4601/20/8/5514">https://www.mdpi.com/1660-4601/20/8/5514</a>
- Tari-Keresztes N, Girdler X, Gupta H, Clarke B, Christie B, Smith J, et al. 'Like a family in the end': Improving mental health Recovery skills through Peer-to-Peer communication in Darwin, Australia. Health & Social Care in the Community. 2022; 30 (6), e5336-5345 <a href="https://pubmed.ncbi.nlm.nih.gov/35949176/">https://pubmed.ncbi.nlm.nih.gov/35949176/</a>

#### Presentations:

- Tari-Keresztes, N., Armstrong, N., Smith, J., Gupta, H., Featherston, P. Peer education and recovery in the Northern Territory, TheMHS, Adelaide, Australia, 15-18 August 2023
- Armstrong, N., Tari-Keresztes, N., Bretherton, R., Smith, J., Gupta, H.: Pilot and Evaluation Recovery Together, AADANT Conference, Darwin, Australia, 23-24 May 2023
- Tari-Keresztes, N. Armstrong, N., Smith, J., Gupta, H. The Circles of Support. AADANT Conference, Darwin, Australia, 23-24 May 2023
- Tari-Keresztes, N. Armstrong, N., Smith, J., Gupta, H., Featherston, P. The journey of the emerging peer initiatives in the NT. Preventive Health Conference, Adelaide, Australia, 02-04 May 2023
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NT Lived Experience Network Darwin, Northern Territory

Care of Noelene Armstrong
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m: 0438 022 032

28.08.2023

Dear NT Lived Experience Network,

### Re: Support Letter for the NT Lived Experience Network's response to the draft NT Lived Experience Framework

As a Carer, I have reviewed your response dated the 25<sup>th</sup> of August 2023 to the draft NT Lived Experience Framework. On behalf of my family I would like to formally provide our support to your response.

I have been a long-term family carer.

My family recognizes the imperative to support the establishment of strong and collective lived experience advocacy bodies to

- Build the capability of their community to participate in systemic advocacy;
- Establish networks across jurisdictions to collate and elevate issues of concern and solutions;
- Champion the experiences and perspectives of the people they represent; and
- Contribute to local and national level decision making.

We believe the NT Government, should recognise and support a lived experience representative body in the NT in the same way that all other state and territory governments have done.

We call on the NT Government to recognise and support the NT Lived Experience Network to establish themselves as the NT lived experience representative body.

Yours sincerely,

Roz Stevens

NT Lived Experience Network Darwin, Northern Territory

Care of Noelene Armstrong
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27/08/23

Dear NT Lived Experience Network.

Re: Support Letter for the NT Lived Experience Network's response to the draft NT Lived Experience Framework

As an interested Party I have reviewed your response dated the 25<sup>th</sup> of August 2023 to the draft NT Lived Experience Framework. On behalf of my expended family I would like to formally provide our support to your response.

I recognize the imperative to support the establishment of strong and collective lived experience advocacy bodies to:

- Build the capability of their community to participate in systemic advocacy;
- Establish networks across jurisdictions to collate and elevate issues of concern and solutions;
- Champion the experiences and perspectives of the people they represent; and
- Contribute to local and national level decision making.

I believe the NT Government, should recognise and support a lived experience representative body in the NT in the same way that all other state and territory governments have done. With the added complexities of remoteness, cultural diversity and socioeconomic barriers that the NT faces compared with other states, it seems even more critical for there to be a lived experience representative body in the NT.

I therefore call on the NT Government to recognise and support the NT Lived Experience Network to establish themselves as the NT lived experience representative body.

Yours sincerely

Paul Britton & the Britton Family