Listening to the people of rural and regional NSW

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The Mental Health Commission of NSW has developed a draft Strategic Plan for Mental Health in NSW that reflects the needs, wishes and priorities of people across the State.

Good old-fashioned listening is an essential part of the process and to that end the Commission held a series of forums with a diverse range of groups and communities across NSW. These Living Well forums were opportunities for people - young, old and in-between - to share their experiences, views and ideas for change. The things we heard were synthesised into documents such as this one, which were then used to refine ideas, to generate more ideas and, ultimately, to inform the draft Plan.

In September and October, three Living Well forums were held to hear what people living in rural and regional NSW have to say about mental health and wellbeing in their communities. They took place in Broken Hill, Tamworth and Nowra and were well attended by a mix of health care workers, people with a mental illness, carers, staff from a range of government and non-government organisations, and members of the community at large.

There was a fair degree of what one forum speaker called “justifiable scepticism” among those who attended. Many people feel they’ve been asked to go over this territory before and nothing useful has come of it. The Commission is well aware of this. We know that what we do needs to be different, with the emphasis on “do”. With that acknowledged, a lot of valuable ideas and perspectives did nonetheless emerge.

1. **Provide better access to services**

People in rural and regional areas feel they are short-changed, and do not have access to basic services that are considered standard in metropolitan areas.

Shortages of appropriate support services, networked together to provide service when it is needed across all age groups, areas and times of day, meant people in rural and regional NSW risked being channelled towards the wrong forms of care, forum participants told us.

Emergency services were called upon too often in the absence of better ways of caring for people experiencing mental distress. And a lack of GPs, especially those who bulk-bill or work out of hours, meant people were sometimes forced to seek emergency care even for routine matters such as needing a new medication script.

*“Police are a de facto mental health service. Ambulance are a de facto mental health service.”* (forum participant)

Service access was haphazard: “You can have good services in one place then 50km out of town there’s nothing.”

2. **Examine the distribution of funding**

There was some concern that funding for mental health and other support services is poorly distributed across NSW. There were calls for more transparency and a sense that rural and regional areas in particular aren’t getting the funding and resources they need.

It was also noted that funding for mental health initiatives needs to be established for the long term, not just in three-year election cycles.
Several forum attendees with first-hand experience said many valuable community-managed organisations providing mental health and allied services in rural and regional NSW are small and operate on a shoestring. Setting them up to compete against each other for funding, which is how it’s done at present, uses up valuable resources, discourages cooperation and results in duplication of services.

There were calls for the Commission to lobby for mental health to be a major focus of the National Disability Insurance Scheme.

3. Clarify and integrate services

Existing mental health services are confusing and difficult to access. This message came through particularly loudly and clearly. Consumers and, sometimes, providers just don’t know where to go for help, particularly before a mental health issue becomes severe or develops into an outright emergency. There were calls for mental health services to be clearly mapped and for comprehensive marketing of those maps to the general public.

Access to GPs came up in this context. GPs, it was said, are “the default system for providing mental health services” which is a heavy burden for them to carry. Furthermore, there are rural and regional areas, particularly in the state’s west, where GPs are in particularly short supply, which adds to the strain. The merit of making GPs and hospitals the main gateways to mental health services was questioned. Self-referral for mental health services was seen as positive but, it was noted, those services actually need to exist in the first place, they need to be affordable and the general public needs to know about them.

A number of people noted that government support services and other agencies operate as “silos” which often results in consumers being bounced between agencies. As the system stands, other pivotal issues that can affect a person with a mental illness, such as homelessness or unemployment, are dealt with separately or overlooked. Many feel like numbers in a maze of inflexible policies and red tape. Services need to be better integrated – particularly mental health, health in general, the justice system and housing services – and collaboration encouraged.

There was particular frustration concerning access to support and services for people with a dual diagnosis, such as an intellectual disability and a mental illness, which falls across two jurisdictions or drug and alcohol dependency and mental illness. And there was concern that higher rates of substance use could create mental health problems that reverberate across generations.

“A lot of mental illness starts with drug and alcohol issues and kids in unsafe households. There’s a need for more drug and alcohol professionals.” (service provider participant)

In summary, consumers want government and other agencies to adopt a more “holistic” and “people-centred” approach. And they want pathways to mental health and allied services to be clear.

4. Step in, follow up and continue the support

There was frequent mention of the need for comprehensive, personalised follow-up services when people exit the mental health system or the justice system. Problems such as homelessness, unemployment and drug and alcohol misuse will often have played their part in an individual reaching a crisis point and are simply waiting to be replayed at the other end.
There was a general consensus that there is a great need for more community-based support that isn’t necessarily “medical” but which helps keep people on track. These might include respite care, supportive home visits and life skills classes. There was some talk of “mobilising” existing community groups to provide some of this support.

5. **Challenge stigma**

The people of rural and regional NSW believe education about mental health and mental illness, starting from primary school, is vital to reducing the problem of stigma and increasing community resilience. Everyone – those with a mental illness, their carers, health workers and the community at large – stands to benefit from being informed about mental illness, being able to talk about it without fear or shame, and knowing where to go for help. So, more education, for everyone, please.

The fear of stigma, and an associated need for privacy, was identified as being particularly important in smaller communities.

“If a young person came in I would probably know them. How confident would they feel about talking to their mother’s friend about a mental illness?” (service provider)

The value of hearing stories or “testimonies” from people who have benefitted from treatment for mental illness was also raised. Stories of recovery, it was suggested, need to be shared more often and might also form a useful basis for public education campaigns.

6. **Support young people**

A great deal of concern was expressed about the mental health and wellbeing of young people in regional and rural NSW.

Devising ways to support young people who do not necessarily have a mental illness but are struggling - and particularly those who do not have a supportive home environment - was seen as a priority. Several mental health case workers said these are the kids at particular risk of developing a mental illness or winding up in the justice system. Suggestions for change included establishing counselling and advocacy agencies specifically for young people, increasing expertise among high-school counsellors and establishing a “one-stop-shop” for youth services. Headspace was raised repeatedly as an example of an organisation that is getting it right. Several people said its holistic model should be adopted more widely.

Online services in particular were seen as an opportunity to reach young people with a mental illness or simply in need of support. Self-determination, it was noted, is important to this age group.

Juvenile detention attracted notable criticism. It was described as a recipe for mental illness. A number of mental health case workers said there is a particular need for follow-up support when young people come out of the system. Many simply return to the same problems they were enduring before they entered the justice system and then plunge back into strife.

“Any child that goes through juvie is going to come out with a mental illness.” (forum participant)

The importance of accommodation for young people with a mental illness was emphasised. Homelessness, it was noted, can both lead to and result from mental illness. Many young people in rural and regional NSW cannot afford the costs of housing and there is a need for more supported accommodation. The Youth Allowance was deemed inadequate.
It was noted that there simply aren’t enough mental health services for young people, or indeed the not so young, in rural and regional NSW.

7. **Reduce isolation**

Employment was named repeatedly as key to feeling like a valued member of society and unemployment was named as a significant issue in rural and regional NSW, particularly for those with a mental illness. Many people with a mental illness do not want to be on a disability pension. They want to engage in meaningful paid work.

Community-based agencies that organise positive social activities - such as supported shopping expeditions and cooking classes - for people with a mental illness were commended and there were calls for more of these. It was also noted that “community friendly” activities dispel loneliness and promote wellbeing generally.

8. **Include older Australians**

Several people said that exclusion from the workforce and feeling “useless” and marginalised are major contributors to poor mental health among older Australians. It was suggested that mainstream Australia could learn a lot from Aboriginal culture when it comes to respecting and including community elders, and benefitting from their experience.

9. **While we’ve got your attention**

Discussion during the three rural and regional Living Well forums was often intense, and lots of disparate perspectives and ideas were raised. Additional issues raised at the forums include:

- More drug and alcohol professionals are needed urgently.
- There aren’t enough after-hours crisis services.
- Mental health and other support services that meet the particular needs of men, young children, people from culturally and linguistically diverse backgrounds (CALD), and people who identify as lesbian, gay, bisexual, transgender or intersex (LGBTI) are particularly hard to find in rural and regional NSW.
- Community case workers are overstretched and burning out. Having more case workers in rural and regional communities to identify needs around mental health, guide people towards appropriate services, or provide direct support, benefits everyone.
- The spaces in which mental health services are provided need improvement. They need to comfort and inspire people, and promote social connection.
- Carers need more support and to be heard.
- Mothers of babies and small children living in rural and regional NSW often can’t get to mental health services. They need support that can come to them.
10. So what to make of all this?

There are, without doubt, lots of areas in need of reform when it comes to mental health in NSW. In the course of these rural and regional forums, however, the Commission has also heard about individuals, programs, organisations and systems that are working. Some may need minor adjustments or to be expanded, and some can be promoted as role models. This is cause for optimism. There were also a lot of ideas on which to base positive change and this is cause for further optimism. The Commission is grateful for the energy and honesty of the people who attended these forums. We still have a lot more to do, but we are excited by the ideas that are emerging and looking forward to seeing them become part of substantial change for the better.