

WHERE DO I START?

MENTAL HEALTH SERVICE ACCESS IN SMALL RURAL COMMUNITIES
IN THE SOUTHERN MALLEE CATCHMENT

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SHORT SUMMARY ABSTRACT

In this action research study, service providers, consumers and carers came together to explore mental health service access in small rural communities. Within the literature there are few examples of these groups working together on service planning. An extensive scoping review was completed to map the evidence base. Interviews with 20 consumers and carers ensured local issues were contextualised. Seven themes emerged: *Try standing in my shoes, Creating a drama, Capability aligned with need, Seeking stability and connection, Unseen and unimportant, Pick your team, and People like me.* Entrenched stigmatizing attitudes evident in small rural communities impacted on the emotional wellbeing of consumers, carers and family members. Barriers to service access included a lack of understanding of mental illness amongst community members, health professionals and emergency service staff. Participants stated that the only way they could get help was in a crisis situation, and they described contacting multiple services for support. A lack of discharge planning and inadequate service coordination was described. Stories were consistently told about how family members were excluded from care. Stigma reduction strategies, service coordination, early intervention to avoid crises, skill and knowledge development of health professionals and other support workers, improved discharge planning, recognition of the role of families and carers, different methods of engaging with people, and a central coordination model were identified as recommendations. The key recommendation is for a multi-sectoral, strategic, whole of system, coordinated, and longitudinal body of work, to implement a planned and coordinated approach in addressing the multiple system failures.

EXECUTIVE SUMMARY

Using a participatory action research design, the aim of this study was to bring together people who design and deliver mental health services, and people who use mental health services, to explore service access in the Southern Mallee catchment. The need to involve mental health consumers and carers in all stages of healthcare design, delivery and evaluation is identified in health policy, but there are few examples of health professionals, service staff, consumers and carers working together to directly address local mental health service planning. This study addresses this gap.

Following ethics approval from La Trobe University Human Ethics Committee, a group of three consumers/carers, four health professionals/service providers, two health service planners and researchers met five times, over a six-month period, with meetings lasting approximately two to three hours. The Executive Officer of the Southern Mallee Primary Care Partnership chaired meetings. The group engaged in extensive dialogue, planning, action, observation and reflection about issues related to mental health service access. All meetings were audio-recorded, with recordings transcribed verbatim and circulated to the group for discussion and confirmation that they were an accurate account of group meetings.

In-depth interviews with 20 consumers/carers who had lived experience of serious and enduring mental illness were undertaken to inform the work of the group. Participants were recruited via media advertisements, and following informed consent processes, were engaged in interviews, with the average length of interview one and a half hours. With the permission of participants, interviews were audio recorded and thematically analysed.

The participatory action research group worked through a three-phase process. In the first phase, an extensive scoping review was conducted to map the evidence base on mental health service access in rural communities. The group discussed a multitude of

consumer, community and health professional factors that impact on service access, with entrenched stigma identified as a major barrier.

In the second phase, the group considered data from 20 interviews and had input into analysis. Seven themes emerged from the data: *Try standing in my shoes*, *Creating a drama*, *Capability aligned with need*, *Seeking stability and connection*, *Unseen and unimportant*, *Pick your team*, and *People like me*. The entrenched stigmatizing attitudes evident in small rural communities impacted on the emotional wellbeing of consumers, carers and family members. Participants discussed a lack of understanding of mental illness amongst community members, health professionals and emergency service staff. Consistently across all interviews, carers described the enormity of the ongoing, persistent pressure and stress that they encountered. Participants stated that the only way they could get help was in a crisis situation, and they described contacting multiple services for support. Enormous frustration was expressed about the knowledge and skill level of professionals that were encountered, including those working in health and emergency services. Whilst, a few examples were given of quality care given by individuals, these experiences were not widespread.

Consistently, a lack of discharge plan and coordination between regional centres and local providers was identified. When services were accessed, the lack of coordinated care was seen as a major barrier to good outcomes. Stories were consistently told of family members being excluded from care and their expertise being ignored. In many cases, carers and consumers suggested they were judged harshly by the professionals they encountered.

One of the most important points made throughout the interviews was that people valued (or would value if it was available) the opportunity to connect with others with lived experience. Consumers were uncertain of any mechanism for them to connect with other people 'like them'. Carers groups were not viewed as able to meet the needs of all people who have family members with mental illness. Carer groups while consistently offered, are voluntary in nature, and are considered self-help options.

The participatory action research group reflected on the interviews, with the lack of service access, coordinated care and need to create crises familiar to group members. The lack of coordinated and integrated care and effective discharge planning was highlighted as a major failing, with discussion occurring around the personal and financial cost to consumers seeking care outside the region.

The major comments from all group discussion were summarised by a person with enduring mental illness who posed a single profound question: *Is it valuing rural and not seeing it as a back-water?*

In attempting to formulate recommendations, the group discussed stigma reduction strategies, service coordination, early intervention to avoid crises, professional development of health professionals, and other support workers, improved discharge planning, recognition of the role of families and carers, different methods of engaging with people, and a centralised point for service co-ordination. However, whilst strategies associated with these issues were identified as crucial, the key recommendation was to stop, piecemeal, band-aid solutions to what is a human rights crisis, and invest proper funding in a multi-sectoral, strategic, whole of system, coordinated, and longitudinal body of work, to implement a planned and coordinated approach to addressing the multiple system failures. The strongest recommendation was the need for this process to include people who live with this system failure every day. In spite of the enormity of the burdens that they carry, consumers and carers expressed a passion for longer-term involvement in a process to address what they described as: *'A nightmare that no-one should have to live with'*.

Whilst this small study was conducted in one rural region in Australia, the opportunities for dialogue and exploration of deeply entrenched issues indicated an urgent need to move beyond tokenistic attempts to engage consumers in health planning, to a system where they are central to all planning processes. Failure to recognise the centrality of consumer participation in all aspects of health service planning, delivery and evaluation will ensure that mental health will remain as a siloed, human rights issue, with a system

that responds, (often badly), to acute episodic crises, but does little to support the notion of psychological wellbeing as a fundamental right of all people, irrespective of geographic location.

On behalf of all project members I am pleased to present our final report

A handwritten signature in black ink that reads "Amanda Kenny". The signature is written in a cursive style with a large, looping 'A' and a long, sweeping tail on the 'y'.

Professor Amanda Kenny

RN Midwife BN Grad Cert Higher Ed Post Grad Dip Mid MN PhD

Enacting mental health policy at the local level: mental health service access in rural communities, an Australian study

INTRODUCTION

In this article we outline a participatory action research study designed to bring together people who design and deliver mental health services, and people who use mental health services, to explore service access for people with serious and enduring mental illness in a large rural area of Australia. The study is a direct response to World Health Organization (WHO) (2013a) demands for local action and leadership, to address inadequate global responses to mental health access. As rural researchers, we are interested in local, community driven responses to health service design, with the direct involvement of people who use services, central to our work.

Our interest aligns with current mental health policy, which identifies the need to involve mental health consumers and carers in all stages of healthcare design, delivery and evaluation (World Health Organisation, 2013a, 2013b). However, enacting this policy at a service level is often inadequate, and success is commonly measured in terms of a tokenistic consumer on a service advisory group (Kidd, Kenny, & Endacott, 2007). Within the literature, there are few examples of health professionals, service staff, consumers and carers working together to directly address local mental health service planning (Kidd, Kenny, & McKinstry, 2014, 2015; Kidd, Kenny, A., & McKinstry, C. , 2015). This study directly addresses this gap.

LITERATURE REVIEW

It is estimated that 25% of the world's population will be affected by a mental illness at some point in their lives, with mental, neurological and substance abuse accounting for 10% of the global burden of disease (World Health Organisation, 2013a). In the Australian context, the location for this study, recent estimates indicate that 2-3% of Australians (approximately 600,000 people) have a severe and enduring mental illness (Department

of Health and Ageing, 2013). In Australia, mental health conditions account for 14% of the health burden, however, less than 7% of health expenditure is allocated to this area (Australian Institute of Health and Welfare, 2014b).

Global estimates indicate that the cumulative impact of mental illness, expressed as lost economic outputs, will total US\$16.3 trillion between 2011 and 2030 (Bloom et al., 2011). Statistical data, however, conceals the full impact of mental health problems on individuals, families and communities, with key reports noting that people with serious mental illness face major stigma and discrimination, and are denied access to basic, essential care (World Health Organisation, 2013a). In countries such as Australia, there are significantly higher rates of disability and mortality for people with mental illness, when compared to the general population (Institute for Health Metrics and Evaluation, 2013), and outcomes for some groups, such as rural and indigenous people are well below what should be expected in a high income country (Australian Institute of Health and Welfare, 2014a).

Recognition by the WHO of the global crisis in mental health (World Health Organisation, 2013b) resulted in an historic global Mental Health Action Plan (2013-2020) that established critical policy direction for mental health service planning. The action plan and resolutions reflected acknowledgement by world leaders of the need to improve outcomes in mental health, with community-based supports central to the proposed actions (Ivbijaro, 2012). It was acknowledged that mental healthcare has, over the last decades, suffered benign neglect, with financial and resource investment inadequate to reverse poor global mental health outcomes (World Health Organisation, 2013a). One of the most important, adopted resolutions, highlighted the need for 'grassroots', local leadership to 'provide comprehensive, integrated and responsive mental health and social care services in community based settings'(World Health Organisation, 2013b).

Whilst the WHO (2013b) highlighted major inadequacies in the management of mental illness in low and middle income countries, a major point was made that poor outcomes for people with mental illness in Western, high income countries reflects failure of these countries to address the issue at a local community level. In countries such as Australia,

critics state that there is lack of political will to address the current 'crisis' in the mental health system (Hall, 2015; Hickie & McGorry, 2007).

In Australia, action to address mental health issues in rural areas is viewed as critical, with people living outside metropolitan areas more likely to experience mental illness, with suicide rates 1.3 times higher outside major cities (Standing Council on Health, 2012). The rate of suicide in Aboriginal and Torres Strait Islander people is 2.7 times higher, than non indigenous. In the age group 15-24 years, suicide rates are 5.1 times higher for indigenous young people (National Rural Health Alliance, 2015). This is a critical issue for Australia, with 67% of indigenous people located outside major cities (Australian Bureau of Statistics, 2011).

For well over a decade, major issues surrounding mental health service access in rural areas have been documented. These include stigma, distance from services, lack of coordinated care, limited consumer involvement in healthcare design, lack of anonymity, lack of skilled health professionals and lack of family and community supports (Judd & Humphreys, 2001; Nicholson, 2008). Given the complexity of the issues identified within key reports, and the broader literature, we were committed to designing a study that would facilitate conversations between people with lived experience of mental health, and service provision, to directly inform healthcare service planning (Abelson, 2001; Anderson, Shepherd, & Salisbury, 2006; Quick & Feldman, 2011).

METHOD

The objective of this study was to engage people who design and deliver mental health services, and people who use those services, to explore mental health service access in small Australian rural communities with populations less than 1500 people. Drawing on participatory, relational epistemology (Heron & Reason, 2006), the use of action research aimed to support dialogue around mental health service access, through consideration of the context, and social world of those who participated (Reason & Torbet, 2001). In participatory research, the researcher and the researched become co-investigators and

work together to help develop the project, collect the data, analyze the data and assist in interpretation and dissemination (Brydon-Miller, Kral, Maguire, Noffke, & Sabhlok, 2010).

In using this methodology, our purpose was to create a democratic process, where power differentials were named and acknowledged, and where the lived experience of all participants could be harnessed to explore how mental health policy initiatives were enacted on a day to day basis (Bergold & Thomas, 2012; Janes, 2015; Liamputtong, 2012). Built into participatory studies is an understanding that the process of participating, and the findings, will be of some benefit to the people within the study, and to the wider community (Kidd & Kral, 2005). The study was outcome focused, with a commitment to developing key strategies to improve integrated, community based mental healthcare across a large geographic region.

THE ACTION RESEARCH GROUP

Following ethics approval from a university ethics committee, letters of invitation to participate in the group were sent to key health and social care agencies across a large rural region. The invitation sought a representative from their agency, and also asked them to identify consumers or carers who might be interested in participating, to contact the research team. A consistent group of nine members, comprised of three consumers/carers, four health professionals/service providers and two health service planners met five times, over a five-month period, with meetings lasting approximately two to three hours. There was acknowledgement that the consumer/carer members were entering a 'power laden space' but the group engaged in extensive dialogue about this, to create an environment for respectful communication where all members were seen as experts.

Consistent with an action research methodology (Brydon-Miller et al., 2010; Reason & Torbet, 2001), the group engaged in extensive dialogue, planning, action, observation and reflection about issues related to mental health access. All meetings were audio-

recorded, with recordings transcribed verbatim and circulated to the group for discussion and confirmation that they were an accurate account of group meetings.

IN-DEPTH INTERVIEWS

Consistent with the focus of this study, in-depth interviews were used to inform the work of the group, by capturing the lived experience of serious enduring mental illness in small rural communities (Kroch & Kahlik, 2006; Minichiello, Hays, & Aroni, 2008). A semi-structured interview schedule was developed based on key themes identified in the literature and included; access to mental health services, barriers and enablers to services, and solutions or alternative approaches that might support better service access.

Participants were recruited via media advertisements, and following informed consent processes, engaged in interviews, with the average length of interview one and a half hours. The interviews were carried out by experienced research team members (AK,SK,VDS,CM) in person (at participants place of residence or another venue chosen by them) or via the telephone. With the permission of participants all interviews were audio recorded and then transcribed verbatim for analysis (Grbich, 2012).

DATA ANALYSIS

Data analysis followed an iterative process (Ezzy, 2002; Grbich, 2012) and was undertaken by experienced qualitative researchers (AK & VDS). The transcripts of action research group meetings, and the individual interviews, were read, and a thematic analytic approach applied. This included line-by-line reading, and extraction of key quotes and text segments related to the questions posed within the group and the interviews (Ezzy, 2002). An initial coding framework from the interview data were developed, and presented back to the action research group for their input and refinement. Following group discussion, final thematic concepts were developed.

FINDINGS

In presenting the findings, we describe each phase of the action research process, the activities undertaken and the resultant group planning, action, observation and reflections.

PHASE ONE OF THE ACTION RESEARCH PROCESS – CONSIDERATION OF THE LITERATURE

In the first phase, an extensive scoping review was conducted to map the evidence base on mental health service access in rural communities. Scoping reviews are useful to map and collate a broad range of literature in a summary format (Arksey & O'Malley, 2005).

The major issues drawn from the scoping review were clustered into key categories and are described in table 1.

Table 1 barriers described in the literature.

Consumer focused barriers	Community focused barriers	Professional barriers
<ul style="list-style-type: none"> • Stoicism • Limited mental health knowledge and understanding • Geographic location • Distance to services • Perceptions of being seen at a 'mental health service' • Ability to maintain long term employment • Lack of knowledge of services provided and how and when to gain access <ul style="list-style-type: none"> • Limited consumer involvement in health care design, delivery, evaluation • Lack of transportation • Limitations on access to child care • Lack of family and community support • Lack of anonymity – concerns about confidentiality, dual relationships • Financial constraints 	<ul style="list-style-type: none"> • Community attitudes to mental illness • Personal and perceived stigma • Self stigma • Structural stigma 	<ul style="list-style-type: none"> • Recruiting and retaining clinicians in rural and remote areas is always challenging and has an enormous impact on service delivery and confidence in the standard of care • Lack of well connected inter-professional care • Regular delays in assessment, diagnosis and treatment • Lack of interest in mental health/GPs not always interested/skilled • Hesitance of health professionals to refer • Bypassing local care serves to further deskill. • Lack of easy access to second opinions • Dual relationships • Focus on high prevalence or low prevalence – often associated with GP interest

Group discussion, planning, observation and reflections

The group had long and passionate discussions about stigma within their small communities. The issue of entrenched stigma created ardent banter between health professionals, service planners and consumers alike. A consumer explained the need to have open and frank discussions that normalize mental illness in the same way as other conditions:

With men they feel ashamed within themselves to say I'm not well. It's extremely hard to say I can't do this anymore ... it's taken me two wives and three kids I still every day talk to someone about it, because I don't want it to bottle up inside me until it bursts. That's what happens which ends up driving some people to suicide – they go so far, they've got nobody to talk to.

A health professional agreed, but reinforced other views within the group that these kind of discussions were extremely difficult to have:

People don't know what to say, I have found in a social situation, when people ask what I do, almost immediately the conversation comes to a complete halt.

There was a great deal of discussion about the risk of community members being open about mental illness. There was a perception that within communities mental illness may be seen as an opportunity to gain a neighbour's property for economic gain, and that within the broader community there is little understanding of support needed for a person experiencing mental illness:

To admit weakness in that context is not economically sound, it's a competitive society. See that more in the farming community. They don't want to talk to their neighbours about themselves.

If a member of the community has an acute medical condition the community will rally around them, however, the same doesn't apply if somebody has a mental illness

The impact on newcomers to the community who had mental illnesses was described as incredibly difficult:

The small communities have expectations, that you like football, and will work on community activities for the town. You have to meet that criteria and if you do then wow you are accepted.

Broader discussion on other barriers occurred within the group, but discussion consistently came back to a lack of community acceptance. Collectively, there was a great deal of enthusiasm for the dialogue that had commenced as a result of this project. The group actions were aimed at having a broader conversation within their own communities, and learning from others with lived experience.

PHASE TWO OF THE ACTION RESEARCH PROCESS – CAPTURING WIDER EXPERIENCES

In the second phase, the group considered data from 20 interviews and had input into analysis. Seven themes emerged from the data: *Try standing in my shoes*, *Creating a drama*, *Capability aligned with need*, *Seeking stability and connection*, *Unseen and unimportant*, *Pick your team*, and *People like me*, with the interviews creating lengthy, conversations within the group. To provide context to the group discussion the following section outlines key interview data considered by the group.

The entrenched stigmatizing attitudes evident in small rural communities impacted on the emotional wellbeing of consumers, carers and family members. A couple that were interviewed described what it was like living in a small community:

We moved up here a few years ago cause we couldn't afford the cost of the city. We came seeking a new life. What did we get? Being called feral and having people stone our roof.

Parents described the difficulties of living in a small rural community with children with mental illnesses:

Well people still to this day, I have been here nine years, still think my son's a monster because he wanders up and down the street talking to himself.

Local, small town gossip was seen to perpetuate feelings of isolation for people with mental illness and their carers/family members:

So everybody knows what's going on and the fact that the police were there. I said I am ringing to let you know. I wanted you to hear the facts rather than gossip from everybody else who's hanging out their windows thinking my gosh what's going on at that house.

A man who had lived with mental illness for many years described the lack of understanding within communities:

And I mean people, most people that don't, do not understand what it's like. It's the most, most hideous bloody disease I've ever come across. I mean it affects you in different ways

Many people talked about how neighbours treated them differently, and how mental illness was considered in a very different way to any other chronic or serious condition:

This is going to sound really selfish but if my daughter have cancer she would have been treated differently. I would have had someone holding my hand and all my neighbours around here would be making casseroles ...We have the Royal Children's hospital appeal that raises millions and millions of dollars, and doesn't it come back to a judgment thing? Mental health is not as sweet and cuddly as kids with cancer

Participants discussed the lack of understanding expressed by others, including health professionals and emergency service staff, and the culture of blame within the community. Carers explained how they were perceived as bad parents:

And then this Doctor rang me and said "She's just a very naughty girl who's seeking attention."

A lack of societal and government understanding was described:

And, and I mean what frustrates me the most is the Government say "We're going to do this for cancer and we're going to do that for breast cancer and we're going do that" and then they'll talk about that, but "Oh people with mental health, oh you ring up BeyondBlue".

Consistently across all interviews, carers described the enormity of pressure and stress that they encountered:

I didn't even know where I was going. At one stage there, this is not bullshit, I was driving ... I come around this corner and I'm just driving along and it was really, really, really getting to me and I saw this big truck coming, coming around the corner and it was a big long straight, I thought I might just line this bastard up and just run straight into it

Despite a lack of support, carers remained committed to their family members

And I've been there fifteen bloody years now, so I don't know what's wrong with me.

Creating a drama

Across all interviews, participants stated that the only way they could get help was in a crisis situation:

It's got to be in a crisis situation ... to really get an appointment, you've basically got to get carted into the ED in the back of a paddy-wagon.

Participants consistently described contacting multiple services to get help:

So I spent like lots of days with her, trying to get her in. She was actually suicidal and she, herself had been ringing around, I don't really know everywhere she rang. But I tried community health, I tried [larger centre], I tried [regional city]. No one I rang could tell me where to get help and in the end I was ringing [regional city]. In the end they said to me "You will have to do what I've done before ... Having her arrested basically...so then I called the police.

Carers described the feeling of living on the edge, not knowing when an incident might happen

You know and I mean you know it's frightening I just can't take anymore, I get stressed I can't handle it

I worry about whom I call. I worry about - oh my god do I need to lock up the knives every night.

When carers are in desperate need of help they perceive that there is nowhere for them to turn:

We will make an appointment for you to go to see them in [larger town] in two weeks time. Not now, two weeks time

There is a real sense of frustration of not knowing who to call for help:

The phone book is the most complex piece of paper you could ever come across when you are in a stressful situation and you are trying to find some sort of assistance and you open up the phone book, and you're thinking it's not sexual, it's not domestic, it's not, and you're going through all these things and you think I just want!

She was suicidal she had a noose in her bag, she was going to kill herself. It was awful but the worst bit was, you don't know who to ring

Capability aligned with need

Enormous frustration was expressed about the knowledge and skill level of professionals that are encountered:

I'm not highly educated or anything like that, but if you rock into ED in [larger town] with your suicidal daughter and you have got no education at all you're ref...

There was discussion that it was not only health service staff that struggled to know how to manage people with mental illness. It was often the police who arrived in times of crisis, but they did not always have the skills and knowledge to know how to manage someone. Examples were given of people being in desperate need but paramedics joking that mental illness is not an emergency. A consumer who had taken an overdose explained:

Yeh and the attitude of the paramedic was just atrocious. He said "Oh it's not an emergency, she's just mental health" that what his reaction was. I had taken an overdose for God's sake. He was like frustrated, frustrated to have to come out to a mental health patient well you know and he just kind of was joking about it and he said "Oh well, yeh mental health, it's not classed as emergency."

Carers expressed frustration that they were aware of services but when they tried to reach out they did not feel their needs were supported:

Beyond Blue, when you ring up, and you are a carer, and you're finding it hard to cope because you're not mentally ill yourself, piss off.

Enormous frustration was expressed about lack of discharge plan and coordination between regional centres and local providers:

Then from [regional city] to [larger regional city], then after my son had endeavoured to commit suicide we were sent home. I was pleased that he was well enough to come home but shocked. Knowing what services people receive for physical illnesses, I was quite amazed that this person who tried to die was sent home

Seeking stability and connection

When services were accessed, the lack of coordinated and consistent care was seen as a major barrier. Participants suggested that the lack of access to a regular local service had an impact on the severity of the next episode:

It could be John Smith this six weeks, in another six weeks it could be Tom Jones

She spent thirty eight weeks at the [major metropolitan service] Yeh I'd spend most weekends down there and at that stage [my son] wasn't home so there was still like we had to like keep the farm going.

But that's another thing you know I've got these other appointments I have got to go to in [regional centre], like to access that service I have to go to [regional centre], to see a psychologist I waited four months to get into see her, so that's just what it's like living around here I guess.

Even when participants had resources to seek care outside their community it was difficult to know how to get help:

There was two guys in [regional centre], one guy just wouldn't return my call and the other guy said that he wouldn't treat anyone under the age of sixteen and at that stage [daughter] was only just fifteen.

Participants were very positive about metropolitan services but frustrated about the lack of services locally. They highlighted the lack of local case management:

On paper [region] looks like it's very well serviced because we have, you know, a lot of organisations that say they provide services for residents, but we don't have any services that actually come into the place. It's all outreach

When things became exceptionally difficult participants indicated the only option for respite care was a nursing home:

Yeh and then he says to me "No worries" he says "We'll give you some respite" he says "We'll whack her up there in [nursing home] with all of the oldies." I said "No, you bloody won't."

Concern was expressed about the lack of follow up in the region:

But there was no follow up and there was no counselling while they were in there, there was nothing. There was, they were just a number, but getting her in there was the hardest and then when we got out... Well that was harder. Well she literally got in the back of the car and she said "Mum I'm really scared" because, she said "I don't know what to do because I will use again, because I will be around you know come back and I will be around..." no support ... but she'd had no counselling and no rehab and no, she was scared, she was crying you know it was awful.

And I said you know she really needs help with rehabilitation and all of that sort of stuff, but they had no real suggestions, so we walked out of there and I did a lot of ringing around and I finally found somewhere.

People were concerned about the trajectory for those who did not get care:

There are kids in there that they're going to roll on from the adolescent system into the adult system into the justice system.

Unseen and unimportant

Stories were consistently told about how family members were excluded from any care or their expertise was ignored:

Actually one of the, it was horrific, I actually I threw a hissy fit and I thought "Oh my God if I don't pull this together, they're going to lock me up."

They just shut the door on, on the family. Like [son] would get discharged they will ring me up. He's coming home and that's it.

And I'm sitting there with a bruised face and all blown up and they didn't even come out and say "This is what's happening."

Pick your team

The importance of who was there to support you and provide care was highlighted:

He [policeman] said to me "Look you can lay charges, but don't go down that path." He could see that we had problems.

So she rings me up and we have a chat. I have met her for coffee when I have been in [larger town].

Examples were given of the small acknowledgements that made a difference:

"How are you going, is there anything?" When [family member] had an admission to [larger town] about twelve months ago the doctor wanted to see me and I went in there and she said "What do we need to do to help you?" I burst into tears.

People like me

One of the most important points made throughout the interviews was the opportunity to connect with others with lived experience:

But if it was a person that's feeling suicidal for the first time they, they need somewhere to go that someone can talk to them

Carers groups for many people were not seen as able to cater to the diversity of people's needs:

And I really admire them but me, me to be sitting around the only bloke there to be sitting around with a group of bloody sheila's having cups of tea and eating scones and things like that, it ain't going to work.

And the thing is you're dealing with this stress you know all the time, all you want to do is go and have a bit of a laugh and a talk...But you don't want to be sitting there listening to whinging all the time.

There was acknowledgment that often carers groups and other local organisations were left to “pick up the pieces” and to offer the only local services to people with mental health issues without training or support

It was like you know great we've got this service in but it's not a service, it's a volunteer group!!

There was agreement that being able to sit and talk to someone who understood on a one to one basis was crucial:

I'm only a lonely old, bloody little old Carer.

Group discussion, planning, observation and reflections

There was much sadness amongst group members when reflecting on the interview data, but little surprise. The lack of service access, coordinated care and need to create crises was familiar to group members who provided their thoughts:

I had to take a whole bottle of sleeping pills, wait for a little bit, and then ring the ambulance. I stayed in hospital for a couple of days, then a mental health nurse came to see me “you didn't really want to commit suicide did you”? “No, I didn't” “Well you're ok to go home then.” Wrong answer.

If they threw a brick through a policeman's window they would get some help. If you go through the normal channels it can be 10 days before you see anyone and by then you could have slit your throat.

The lack of coordinated and integrated care was highlighted as a major failing, with discussion occurring around the cost to consumers of seeking care outside the region.

The cost if you're a private patient is \$200 - \$120 comes back from Medicare and then the cost of how fuel for the round trip, there is very little left out of a fortnightly pension.

Cancer care is different, if you have to travel to Melbourne for oncology there is

accommodation and different things like that.

A clinician expressed her frustration:

I triaged him and he has also triaged himself on several occasions. They wanted this client to drive to see their clinician and he was extremely unwell, heavily medicated on extremely high levels of anti-psychotics. I am actually going to ask him to write a complaint, because the treatment and judgement he received from the clinician was absolutely disgusting.

Long discussions were held on the lack of education amongst health professionals, and other support workers. There was resounding agreement that coordinated, recovery focused care for mental illness is rare:

The lack of education coming through from the GPs is one of the major stumbling blocks. If you're diagnosed with diabetes you are immediately sent off to the diabetes clinic to see a nurse

There was group discussion on telehealth solutions, with everyone agreeing that it cannot replace face-to-face support. It is often used badly, by placing an isolated consumer in front of a screen:

Even if it was a local clinician, albeit a psych or social worker, or nurse even. If they were supported by a psychiatrist by videoconference the continuity being the local clinician. Once the local clinician is gone, you're stuffed.

The major comments from all group discussion was summarised with a single profound question:

Is it valuing rural and not seeing it as a back-water?

PHASE THREE OF THE ACTION RESEARCH PROCESS – CONSIDERATION OF POSSIBLE STRATEGIES AND DEVELOPMENT OF RECOMMENDATIONS AND FUTURE ACTION.

In attempting to formulate recommendations, the group discussed stigma reduction strategies, service coordination, early intervention to avoid crises, professional development of health professionals and other support workers, improved discharge planning, recognition of the role of families and carers and support for them, different methods of engaging with people, and a central point for interconnection. However, whilst strategies associated with these issues were identified as crucial, the major recommendation was to stop, piecemeal, band-aid solutions to what is a human rights crisis, and invest in funding a multi-sectoral, strategic, whole of system, coordinated, and longitudinal body of work, to support a planned and systematic approach to addressing multiple system failures. The strongest recommendation was the need for this process to include people who live with this system failure every day. In spite of the enormity of the burdens that they carry, consumers and carers expressed a passion for longer-term involvement in a process to address what they described as:

A nightmare that no-one should have to live with.

DISCUSSION

In a policy environment that highlights the centrality of consumer participation in all stages of healthcare design, planning and evaluation (Commonwealth of Australia, 2012; Department of Health and Ageing, 2011; Green, Price, Lipp, & Priestley, 2009; Kulig & Williams, 2012; National Health Hospitals Reform Commission, 2009; World Health Organisation, 2010), there is acknowledgement by government of a lack of clarity on how participation policy agendas can realistically be achieved (Francis, 2013; Mitton, Smith, Peacock, Evoy, & Abelson, 2009; Victorian Auditor General, 2012). A recent review of

community participation in rural health (Kenny et al., 2013) indicated few studies that report participation beyond the levels of tokenism, described in the seminal work of Arnstein (1969).

At first glance, the dearth of research in the area of consumer participation in rural regions of high-income countries would seem surprising. Prominence is given to consumer participation in global health policy reform (Committee on the Future of Rural Health Care, 2005) (Commonwealth of Australia, 2012; Kulig & Williams, 2012; Wagstaff, Lindelow, Wang, & Zhang, 2009; World Health Organisation, 2010), based on contentions that rural communities are fertile grounds for participatory processes (Organisation for Economic Co-operation and Development, 2010). However, at a practical level, there is acknowledgement that meaningful participation is not easy (Kenny, Farmer, Dickson-Swift, & Hyett, 2014), and that creating participatory spaces for consumers and organisations to work together is a challenging undertaking (Eversole, 2011).

The action research process described in this article is unique, in that participatory processes generally involve 'usual suspects', who are confident in power compromised social settings (Kenny et al., 2014; Taylor, Wilkinson, & Cheers, 2006). Whilst the action research process we used, was built around an 'invited space ... structured and owned by those who provide[d] them' (Cornwall, 2008), we drew on the work of Kilpatrick (2009) to develop a strong governance mechanism and actively recruited and supported a small group of consumers who were strongly engaged in the process. It has been argued that mechanisms to engage people who are marginalized continue to be elusive (Taylor, Wilkinson, & Cheers, 2005) and most fail to achieve inclusive participatory processes (S Kidd, A Kenny, & R Endacott, 2007; Kilpatrick, Cheers, Gilles, & Taylor, 2009; Taylor et al., 2006). Whilst authors have suggested that rural people are 'increasingly wary of being involved' in participatory activities (Beresford, 2002), this was not our experience.

An important part of the initial establishment of our group was explicit acknowledgment that all members were 'experts' and lived experience was valued as highly (or more highly) than 'professional knowledge'. We were explicit about unequal power relationships (Turner, 1987), being cognizant of harsh criticisms that have been directed

at psychiatry for perpetuating biomedical dominance (Bracken & Thomas, 2001; Cutcliffe & Happell, 2009; Foucault, 2002; Turner, 1987; Willis, 1994).

Whilst the group worked hard to create a participatory space (Eversole, 2011), where people were respected, and open dialogue was encouraged (McArdle, 2008), the findings from our study indicate that mental illness, more broadly, continues to be conceptualized through a biomedical lens, with only cursory consideration given to the psychological, environmental and social realities associated with its enduring nature.

Well over a decade ago, Judd and Humphreys (2001) stated, that a major priority of Australia's then National Mental Health Strategy (Australian Health Ministers Advisory Council Evaluation Steering Committee, 1997), was service access to rural mental health care. In Australia's Fourth National Mental Health Plan (2009-2014) service access, coordination and continuity of care continued to be key priority areas (Australian Health Ministers, 2009). The actions in this fourth plan included the development of strong partnerships between 'service providers, consumers and carers and other relevant stakeholders to develop local solutions to better meet the mental health needs of communities' (Australian Health Ministers, 2009).

It is clear, that formal documented processes, such as the action research work described in this article, are rare (Kidd et al., 2007; Kidd et al., 2014, 2015; Kidd, Kenny & McKinstry, 2015). However, authors reinforce the major gains that can be made by increasing public input into the design of healthcare (Quick & Feldman, 2011), particularly when addressing complex service issues (Abelson, 2001; Anderson et al., 2006). Despite decades of government policy, focused on consumer participation in rural mental health (Australian Health Ministers, 1992, 1998, 2003, 2009; Australian Health Ministers Advisory Council, 2013), at this point, there appears to be a failure to capitalize on this potential.

Whilst communication and information flow between all sectors of the healthcare system, continuity of care and co-operative service models are highlighted as central to

achieving equitable, universal access, irrespective of age, gender, position or geographic location (World Health Organisation, 2012), there is a consistent message in the data from this study that effective service co-ordination remains an elusive goal.

Within the findings of this study there is data to support a strong critique of key notions of rurality. In Scotland, it was indicated that people with enduring mental illness often move toward urban centres, due to declining social status or to access services (Nicholson, 2008). In our study, the opposite was true. Many of the participants in this study, had moved to the area in search of cheaper housing and reduced living costs. Authors (Farmer, Currie, Kenny, & Munoz, 2015) have identified a major shift in rural demography, with in-migration from people facing disadvantage. The resultant impact of this is that people with the greatest need, are at the greatest distance from needed services, and face some of the highest barriers to service access.

'Rural', conceptualised in bucolic and idyllic terms, does not reflect the reality of the region in which this study was conducted. Descriptions of homogenous, welcoming rural communities (Cohen, 1985), classically represented in the notion of *gemeinschaft* (Tonnies, 2001), were not evident within this study. People told gut-wrenching stories of stigma, prejudice and discrimination. The issue of stigma, associated with mental health, is consistently featured in the literature and key policy reports. From this study, the findings would indicate that despite decades of campaigning for the human rights of people with mental illness (World Health Organisation, 2013b), little gains are being achieved in changing entrenched community perceptions, with mental health consumers and carers devastated by systemic discrimination and societal prejudice (Pescosolido, 2013; Ridgeway, 2001).

It would be naïve to propose a simple solution to address sustained discriminatory practices and attitudes surrounding mental illness, but the data presented in this article suggests a need to conceptualize mental illness in a different way. Key reports focus on mental disorders (World Health Organisation, 2013b), and this reinforces biomedical approaches to mental illness. There is little doubt of the importance of medical management of acute and enduring mental illness, however, participants in this study indicated that mental illness was perceived differently to other chronic conditions. By

conceptualizing mental illness as a chronic condition, there are opportunities to improve discharge planning, self-management and recovery focused programs, to ensure that rural people are not left languishing when acute episodes subside. Conceptualisations of mental illness in this way may go some way to improving pathways into and out of the mental health system and may enable a greater focus on rehabilitation (Jablensky et al., 2000). It is intriguing that rehabilitation, associated with other chronic conditions such as myocardial infarction are well established, yet participants in this study indicated a total absence of programs following discharge from acute mental health facilities.

The findings from our study would suggest that considerable work is needed to achieve the WHO (2013b) vision of a multi-sectoral approach where:

services support individuals, at different stages of the life course and, as appropriate, facilitate their access to human rights such as employment [including return-to-work programmes), housing and educational opportunities, and participation in community activities, programmes and meaningful activities.

In our study, there were isolated examples of service excellence, reflected in the theme 'pick your team', but it is not unreasonable to expect that people, irrespective of geographic location, are not reliant on the 'luck' of encountering a supportive provider. Whilst calls for ongoing education of health professionals (Jelinek, Weiland, Mackinlay, Hill, & Gerdtz, 2011) and initiatives such as telehealth (Hazelton, Habibis, Schneider, Davidson, & Bowling, 2004) have merit, current piecemeal approaches to addressing the social inequalities associated with mental illness, will do little to address the rapidly rising health, social and economic burden (World Health Organisation, 2013a) associated with inaction. In the Australian context, harsh criticisms are directed at Government for their apathy and failures to demonstrate major leadership in addressing the disparities associated with mental health (Hall, 2015; Hickie & McGorry, 2007). The same criticisms are directed at all major Western countries (World Health Organisation, 2013a). Whilst the current level of issues associated with mental illness should be viewed as a human rights crisis, waiting for government action will see the crisis deepen.

Conclusion

Whilst global policy highlights the need for urgent action to reverse decades of benign neglect of mental health services and care, this study reinforces the need for localised, systematic and multi-sectoral approaches to addressing the crisis situation that was consistently described by participants. In a system dominated by biomedical thinking, the need to involve people with lived experience of the system in planning and decision-making is critically important. However, prioritising professional knowledge over the expert knowledge of people who struggle for service access will do little to address structural, systemic and entrenched apathy, stigma, and prejudice. Whilst this small study was conducted in one rural region in Australia, over a relatively short period of time, the opportunities for dialogue and exploration of deeply entrenched issues indicated an urgent need to move beyond tokenistic attempts to engage consumers in health planning, to a system where they are central to all planning processes. Failure to recognise the centrality of consumer participation in all aspects of health service planning, delivery and evaluation will ensure that mental health will remain as a siloed, human rights issue, with a system that responds (often badly) to acute episodic crises, but does little to support the notion of mental wellbeing as a fundamental right of all people, irrespective of geographic location.

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