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1

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## PROJECT REPORT

# Out back and out-of-whack: issues related to the experience of early psychosis in the New England region, New South Wales, Australia

#### **RL Wilson**

Hunter New England Health, Armidale, New South Wales, Australia

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Wilson RL

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## ABSTRACT

Context: The slow slide into a first episode of psychosis is often difficult to detect and is often described in retrospect as the point at which things were *not quite right*. A rural setting can add an layer of complexity to detecting early psychosis, with local structural issues and other disadvantages potentially complicating both identification and early treatment. Fewer specialist workers are available in rural communities compared with urban communities, and drug and alcohol usage can mask the early signs of prodrome (early psychosis symptoms). Along with these more predictable contextual issues, family and drought conditions can impact significantly the mental health of vulnerability rural populations. The use of a vignette provides a window to the lived experience of early psychosis in rural communities. This article explores these issues in the context of northern New South Wales, Australia.

**Issues:** Embedded rural health workers are uniquely positioned to work with local people. One way to address access issues and the lack of diversity among available healthcare practitioners is by recognising and nurturing generalist health workers in all disciplines in their *specialist* role as generalist. It is also important to recognise the natural processes of a rural community with regard to a sense of community, structures and networks, and to accommodate these when planning mental health services.



The International Electronic Journal of Rural and Remote Health Research, Education Practice and Policy

**Lessons learned:** The development of generalist health workers to undertake supported early identification of psychosis in rural communities is a useful strategy. In practice, a key feature is the availability of a specialist project worker. In addition, it is important to continue to advocate for services to rural communities that aim at preventing psychiatric illness, as well as optimising continuity of care for rural residents.

Key words: Australia, early identification, early intervention, early psychosis.

## Context

#### Vignette

David (19 years old) just didn't get the jokes at the pub. The 'lights were on but no one was home'. He had started to ask the blokes he hung out with what the jokes meant, and even then he couldn't get it.

Back at school he used to do OK, especially in maths, he had ideas about going to university. But that is before he dropped out of school half way through year 12. It became too hard to walk into the school grounds and sit in the classroom when people were watching him, and with them plotting to kill him. Sometimes he would get so worked up about it all that his heart felt like it would jump out of his chest, and he would simply have to leave the busy classroom and call his Mum to pick him up early again. He had become a bit of a regular in sick bay at school. Things got worse when people he didn't know started to tell him to do things to his family - things that would hurt them, or even kill them. Even scarier was that people would say these things but hide from him -he couldn't see them but he could certainly hear their demands. If he put on his MP3 player he couldn't hear them so well, so that helped for a little while. But he knew they were still around, wanting him to obey them. Slowly, it dawned on him that Mum and Dad were part of a terrible conspiracy, and that they too wanted to get rid of him. They had figured out who David really was, that his purpose was to save the world, and that only he could do it. They, though, were the enemy. And now they could even

read his thoughts so they knew ahead of time his every next move. It would be very hard to find a way to save the world while they were around.

David was becoming increasingly 'odd' to everyone who knew him. The problem is that David lived in a small country town, where lots of the local population either knew or knew of him and his family. They all know something was not quite right and hasn't been for a while. Some people in town thought it was something to do with the 'pot' David was smoking but others thought he just turned out to be a 'bad apple'. In his small country town there were no specialist young person mental health services based locally, there was only one GP, one community nurse, and a small aged care residential service. Health workers did outreach to the town but this was frequent. There was a part time youth worker/counsellor attached to the high school but she also provided services to other schools in distant towns.

David is the son of a station hand. His mother does part time office work for a stock and station agency. David is the oldest of three children. He lives with his family on a sheep station 30 km out of town and has not been able to find full-time work since leaving school last year. He was offered a casual job cleaning at the pub but he only turned up a couple of times and the pub owner has stopped calling him. David has started to stay home more and more and old friends are dropping off. He is thinking of doing a bit more pig shooting and has easy access to a gun. What can be done help David?



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The scenario presented in the vignette, while fictitious, is not an uncommon story in rural areas; in the northern region of New South Wales (NSW), Australia, it is a familiar set of events. The vignette portrays David on a slow slide into his first episode of psychosis. It is often difficult to identify 'prodrome' (the subtle emergence signs associated with psychosis), in any setting. However, it is more difficult to identify prodrome where access to services is limited by physical distance, and the reduced number of relevant health professionals characteristic of large sized health service areas. This slower process of diagnosis can have a detrimental affect on the duration psychosis, severity and long-term prognosis<sup>1,2</sup>.

#### Identification of prodrome

Identifying prodrome in small communities is problematic<sup>3-5</sup>. Recognising the development or onset of the 'not quite right' behaviours, which indicate prodrome in young people, is always difficult<sup>2,6</sup>. Often, the emergence of psychosis is concurrent with drug and alcohol dependence<sup>7</sup>. Australian prevalence research suggests that in those diagnosed with psychosis, tobacco and alcohol are four times more likely to be involved, and cannabis six times more likely to be involved<sup>7</sup>; and that drug and alcohol usage may delay the early identification of prodromal symptoms<sup>2,6,8-12</sup>. Rural communities, characteristically structurally disadvantaged (with deficits in vocational, educational, recreational and service delivery), are likely to be less able than urban communities to respond to emergent psychosis among young community residents<sup>13</sup>, as illustrated by the vignette.

Small communities have some unique - helpful and unhelpful - characteristics, for example social proximity. Social connections can be remarkably close even when physical distance is isolating, in contrast to the urban experience<sup>14</sup>. However, both the density and variety of services are usually higher in urban areas<sup>13</sup>. Specialist workers and teams are more likely to be situated in urban areas, whereas the rural workforce is more generalist<sup>4</sup>. In the rural population, mentally ill clients are likely to enter

services following a longer period of untreated psychosis<sup>3,4,15</sup>.

One way the Hunter New England, Northern Region Early Psychosis Project is seeking to address this problem is to promote early identification of the 'not quite right phase' among health professionals and other sectors. For example, by providing on-site support to clinicians across the targeted physical region, a specialist project worker (clinical nurse specialist) is able to support early assessment processes. By promoting and distributing information in seminars, an across-discipline capacity is built with a uniform clinical approach to the issue. When generalist health staff from a range of disciplines have a broader knowledge of early psychosis and early interventions, early identification is more likely. Support is also provided to schools, and other government and non-government organisations, with the goal of capitalising on the social connections in each rural community. This 'broad-brush stroke' approach is aimed at supporting and developing individuals who have an interest in the topic, with a view to fostering early identification practices. This generalist model has previously been identified as suitable for use in rural communities<sup>2</sup>.

#### Family, drought and other rural vulnerabilities

The rural family has had many challenges in recent times. Times of drought place a particular stress on the mental health of many rural people. Rural communities rely heavily on the success of agribusiness and the whole community suffers when this vital economy in decline<sup>16</sup>.

Suicides, drink driving accidents, depression, alcohol consumption and cigarette smoking are all significantly higher in rural communities <sup>17,18</sup>. What might underlie this? In 2005 in the northern NSW region, for example, the number of first-episode psychosis clients treated was sevenfold what might have been expected.



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## **Issues**

#### Access to services

The northern NSW rural setting contains many very small communities that are separated from neighbouring communities by significant distances. This physical, geographical isolation poses a significant barrier to early identification and early intervention<sup>19</sup>, for the populations of the smaller communities often would not support the placement of a permanent resident worker.

Child and adolescent mental health services are provided to this northern community using a 'hub and spoke' model. Two key hubs are established in regional cities Tamworth and Armidale, and these communities serve as a base for service delivery with outreach to the smaller communities.

Even so, some barriers to accessibility remain. Rural social proximity can preclude early identification<sup>14</sup>, when local people are reluctant to seek mental health assessment in order to avoid identification and the stigma associated with seeking help<sup>13,20</sup>. Rural people, especially males, often have a stoism that makes them reluctant to seek assistance, as this may be viewed by themselves or others as a sign of weakness<sup>3,13,19</sup>.

A variety of services and health workers are critical in the early identification of psychosis – for example, youth workers, school counsellors, GPs, welfare organisations<sup>4</sup> – and in very small communities without such a variety of such services early identification opportunities may be missed<sup>5,19</sup>.

## Generalist health worker as specialist

Historically, most disciplines have developed a silo of knowledge or 'speciality', with the associated assumption that a generalist had less 'speciality'. In the rural setting, however, health workers have a *unique opportunity to specialise as generalists*<sup>2</sup>, with the typical development of

professional skills that cover a broader scope of service delivery than their urban counterparts. Consider, for example, the community nurse, traditionally a central and constant healthcare worker in small rural communities. While many other health workers in rural communities are more mobile, often this nurse has been a long-term community resident, offering grounded and constant of healthcare delivery. In this situation, the nurse's adaptability and coverage of a broad range of health needs (through out the life span, across health streams, and clinical situations, including addressing prevention and chronicity) leads to the acquisition of unique specialist skills through practice exposure. This has significant therapeutic benefits for the community.

By acknowledging the specialist role that such generalist health workers play, a great depth of capacity can be harnessed in early identification of psychosis. Extending the concept to intersectorial collaborations (eg among rural communities, health service planners, GPs, allied health workers and nurses) may also address the issue of barriers to good mental health early interventions<sup>19</sup>.

Inherent in recognising the role that generalists play, is the acknowledgment that there is no particular mystery in providing early intervention strategies for early psychosis<sup>6</sup>. While health specialists may lean towards silo-style protection of their knowledge base, generalists are expert in picking out the most useful aspects and applying them in local rural settings<sup>2</sup>. This practice needs to be encouraged, and this is certainly a goal of the Northern Region of Hunter New England Health. While supporting a generalist model is a significant challenge, the strategic and dedicated clinical specialist project worker harnesses the abilities of generalists in the area of early identification of psychosis.

## Community support services, structures and networks

Sense of *community* is a strength in rural communities, and is a concept often attested to in defence of rural town lifestyle. This unifying sense of community runs deep and is especially apparent when protecting and supporting



The International Electronic Journal of Rural and Remote Health Research, Education Practice and Policy

community members overtaken by disaster or hardship (eg drought, flood, fire, trauma, loss).

The structure and networks of a rural community are developed through shared experience, word-of-mouth, and promoted by social proximity<sup>20</sup>. Because of this, they can be difficult to map. However, local individuals know how information is exchanged and support provided. This information and informal network is a critical aspect of rural small community life, and provides a key opportunity to link into early intervention and identification work. By working with this natural process and developing community interest, the stigma attached to mental health issues may be reduced, and individuals such as David may be assisted in a timely fashion.

## Lessons learned

#### Implications for successful service provision in the future

In the early phase of early psychosis project work within the northern NSW region, a number of challenges and opportunities have been identified. The distinct differences of rural communities compared with urban communities are reflected in service planning. It is extremely unlikely that specialist early psychosis clinicians will ever be in abundant supply throughout this region; however, the generalist health worker population represents an underdeveloped asset with spread across the region. With carefully tailored specialist clinician support, such richly skilled health professionals and a host of informal networks offer opportunities for improved early intervention and prevention.

In conjunction with our model of service delivery, it is important to continue to call for redress of the inequities suffered by rural communities. There is a need for more services aimed at preventing psychiatric illness<sup>19</sup>. In particular there is a need for a greater integration of mental health and drug and alcohol services, especially in regard to vulnerable young rural people<sup>7</sup>.

When these lessons are learned, hopefully rural people like David and his family will face fewer barriers to good early identification and early intervention in response to emerging psychosis.

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The International Electronic Journal of Rural and Remote Health Research, Education Practice and Policy

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