Submission to Standing Committee on Health into Best Practice in Chronic Disease Prevention and Management in Primary Health Care

Thankyou for the opportunity to present this submission to the Standing Committee on Health into Best Practice in Chronic Disease Prevention and Management in Primary Health Care. The La Trobe Rural Health School is Australia's largest, multidisciplinary rural health school, with world-class rural researchers in consumer/community participation, mental health and developmental disability. Given this expertise, the focus of our submission is the **rural context, mental health and disability,** framed by our world-class **consumer/community participation** research agenda.

In reading current submissions to the Inquiry, we note a wealth of quality submissions focusing on areas such as diabetes, heart disease and asthma. These are obviously important, but we urge members of the Standing Committee to broaden their conceptual thinking to **chronic conditions** and recognise the importance of the rural context in their deliberations.

The importance of terminology in conceptualising chronic conditions

Whilst we applaud the Parliament of Australia in undertaking this Inquiry, we argue that the term **chronic disease,** that frames this Inquiry, is inconsistent with key global policy documents that indicate the need for an urgent paradigm shift, away from the limited focus on **chronic disease**[1]. Over a decade ago, the WHO[1] argued that the global focus should be on chronic conditions:

> Chronic conditions are no longer viewed conventionally (eg. limited to heart disease, diabetes, cancer and asthma), considered in isolation, or thought of as disparate disorders ... chronic conditions therefore include non communicable conditions, persistent communicable conditions, long-term mental disorders and ongoing physical/ structural impairments.

It is intriguing that key Australian Government publications[2] (drawing on the WHO report) have stressed the importance of this shift from *chronic disease* to *chronic condition* to reflect global best practice, but the title and terms of reference for this Inquiry do not reflect this shift.

Reconceptualising chronic conditions

Our point is not simply a correction of language, but supports our argument for a paradigm shift in conceptualising chronicity beyond 'neat' biomedical diagnoses. We have read with interest the submissions to this Inquiry (to this point). In particular, the useful and important submission by the Australian Government Department of Health was an interesting read. Whilst there were valid and important points made, five chronic conditions were listed that account for 'around 80% of the total burden associated with chronic disease: cardiovascular disease, diabetes, asthma and other chronic respiratory conditions, chronic kidney disease, arthritis and musculoskeletal'[3]. This again is intriguing, in that global statistics indicate that by 2020 the only chronic condition that will surpass mental illness (in terms of burden) is cardiovascular disease[4].

The WHO argues that an 'evolution in primary health care'[1] is needed to address system, population and financial threats associated with chronic conditions. We argue that an evolution in conceptualising *chronic conditions,* beyond the biomedical term *chronic disease,* is central for Australia's health planning. Consistent with WHO definitions, chronic diseases are medical diagnoses that are an important subset of chronic conditions. Limiting health policy and planning to this subset perpetuates a biomedical lens on acute and episodic management, thereby detracting from consideration of the psychological, environmental and social realities associated with living with chronic conditions. In defining chronic conditions, we utilise the WHO definition[1] of conditions that persist and require some level of healthcare over time. Importantly for this submission, we note that in their definition, the WHO includes conditions such as schizophrenia.

Reconceptutalising the notion of rural

There is a solid body of evidence that points to issues associated with the delivery of rural healthcare, including geographic isolation, inequitable service access, and lack of health professionals[5.] Still, 'rural' continues to be conceptualised in bucolic and idyllic terms: that is, rural communities as homogenous, welcoming and connected[6]. Whilst this notion may encompass some rural communities, our recent rural research indicates a major shift in rural demography, with in-migration into small rural communities impacting on the social, economic and structural fabric of these communities[6]. In other studies that we are undertaking [7], there are indications that the cost of living in metropolitan cities is encouraging people to move into rural regions, often resulting in those with the highest need at the greatest distance from support services. In the area of intellectual and developmental disability, it has been argued that people face the double disadvantage of disability and living in communities where there is social and economic disadvantage[8]. Changes in rural demography are illustrated in our region using the example of the Urban Centre and Locality (UCL) of Heathcote. In this area, 30% of the population lived outside the UCL in the five years prior to the completion of the current 2011 community profile[9].

Our focus on mental health and disability

We argue that people with serious and enduring mental health and intellectual disability (and other lifelong developmental disabilities) must be included in health policy and planning related to chronic conditions. The absence of mental health conditions and intellectual and developmental disability from the *National Strategic Framework for Chronic Conditions*[10] fails to reflect the serious, enduring, chronic nature of people's experiences, or the poor outcomes of co-morbidities evident within these population groups[11, 12]. Specific acknowledgement of the unique nature of the rural environment must occur in the development of this framework to reflect the reality of the people with the most complex needs, who face the highest barrier to service access.

Rural mental health

In 2013, the WHO[4] demanded local community action to address the inadequacy of global responses to serious and enduring mental illness. In the Australian context, it is estimated that 600,000 Australians live with serious and enduring mental illness[13]. On a global level, it is estimated that the impact of mental illness, in terms of lost economic output, will total US$16.3 trillion dollars between 2011 and 2030[14]. In Australia, the rates of disability and mortality for people with mental illness are significantly higher than the general population[15]. Studies indicate that the mortality gap between the general population and people with serious and enduring mental illness is 25 years, with increased morbidity and mortality largely attributed to medical conditions associated with modifiable risk factors[11].

In a recently completed study (Professor Amanda Kenny and colleagues, September 2015), focusing on service access for people with serious and enduring mental illness in the Southern Mallee catchment of Victoria[7], La Trobe University researchers described a human rights crisis. The lack of discharge planning, service co-ordination and lack of connections between the acute and primary health system resulted in what consumers described as: *a nightmare no-one should have to live with* (mental health carer). Consumers and carers stated that creating a crisis was the only way to access care - *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 (mental health carer)*; *you've basically got to get carted into the ED in the back of a paddy-wagon (mental health consumer)* - and that stigma - *I have been here nine years, and everyone still thinks my son's a monster (mental health carer)* - is rife, even amongst health professionals - *Yeh and the attitude of the paramedic was just atrocious. He said "Oh it's not an emergency, she's just mental health" that was what his reaction was. I had taken an overdose for God's sake (mental health consumer).* Consistently it was reported that no services were available to support recovery: *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 with nothing.*

This study was unique in its design with mental health consumers, carers, health professionals, service planners and researchers working together using participatory action research processes. In this study, participants noted that mental illness is perceived differently to other chronic conditions, with rural people left languishing when acute episodic mental illness subsided. It was noted that whilst strategies to support people with chronic diseases, such as heart disease and diabetes, are well established, there is a complete absence of programs to support people discharged from acute mental health facilities, or those living with serious and enduring mental illness.

Intellectual and developmental disability in rural areas

High rates of secondary conditions have been documented for people with intellectual and developmental disability[12, 16]. For two decades, concerns have been expressed about failures to diagnose co-morbid and secondary chronic conditions in these groups, or to mismanage conditions if diagnosis does occur[17] . Over the last decade, researchers have indicated few improvements in this area[18]. The impact of these conditions on people's lives are significant, and cause major limitations that detract significantly on their ability to fully participate in life[12].

In rural areas, access to primary health services, and health professionals who have knowledge and skill to provide services to people with intellectual and developmental disabilities is particularly problematic[19, 20]. People with intellectual and developmental disabilities are high end users of primary health services, with data indicating that they visit GPs up to 54 times a year[21]. It is concerning, however, that general practitioner uptake of Medicare item numbers for extended consultations for people with intellectual and developmental disabilities is limited[22] and outcomes remain poor [21].

In our work, stories of the significant service access barriers that people with intellectual and development disability face are common, with stories of system failure regularly reported. Parents of adults with intellectual disability report a complete inability to access local mental health services for their sons and daughters. They often have to travel to Melbourne to access an assessment and review service, but this is only after a long wait. There are few general practitioners who know who

to refer to, and many have little knowledge or understanding of appropriate services. A recent example of service absence is a mother who had to threaten DHS to provide a service (saying she would leave her son at their door), after her son had a psychotic episode while they were on the Calder Highway. She was driving, and they were both almost killed. The local hospital where she sought immediate help indicated they could not assist, and suggested she should seek help from disability services, who, as noted, were unresponsive.

Prioritising health professional knowledge over the expert knowledge of the consumer and carer

Key policy documents outline the centrality of people who use healthcare in all stages of health care planning, delivery and evaluation[5, 23, 24]. Whilst Government have identified a lack of clarity about how participation with the broader population will be achieved realistically[25], for vulnerable populations there is little knowledge or will to support them to participate in service planning[26]. In our recent studies [7, 26-28] with vulnerable groups, participation has been welcomed by those keen to share their experiences of poor primary health service access, but there is an absence of knowledge of how lived experience from vulnerable groups can be incorporated in service planning for chronic conditions. We argue that failure to recognise the centrality of consumer participation in all aspects of chronic condition service planning, delivery and evaluation will ensure that vulnerable populations will remain siloed, the outcomes of which will continue to be poor health.

Comments related to the specific terms of reference

In the section below we make comment on each of the specific items in the terms of reference for this Inquiry.

1. Examples of best practice in chronic disease prevention and management, both in Australia and internationally:

- To ensure that Australian policy and practice reflects global policy, chronic disease prevention and management must be conceptualized in terms of chronic conditions.
- It must be acknowledged that people with mental illness and intellectual and developmental disability face complex issues, with morbidity and mortality outcomes much poorer than the general population. These groups are central

to considerations of chronic conditions; ignoring the complexity of the issues that they face will only result in a greater Australian disease burden.

- In formulating recommendations, the Standing Committee should draw on evidence that indicates a 'one size fits all model' is inappropriate in the rural context. Simply implementing ad hoc 'generic' programs into rural areas shows a lack of understanding of the impact of geographic distance, and other issues of rurality.
- There must be recognition that 'best practice' requires a multi-sectoral, strategic, coordinated and longitudinal approach to chronic condition prevention and management, particularly in the rural context. Piecemeal solutions simply perpetuate current multiple system failures without addressing core issues, such as whole of region service coordination.
- Stigma reduction strategies, service coordination, early intervention to avoid crises, professional development of health, support and emergency workers, improved discharge planning, a stronger connection between the acute and primary health sector, recognition of the role of families and carers, different mechanisms of engaging with a diversity of populations and regional level service coordination are important in best practice planning.

2. *Opportunities for the Medicare payment system to reward and encourage best practice and quality improvement in chronic disease prevention and management:*

- Tinkering with Medicare item numbers will not address the more fundamental system reform that is required. Whilst funding models and reward are important, methods of reimbursement will not solve major issues associated with lack of service integration and coordination in rural areas.
- Medicare funding models centered on medicine reflect an outdated view of the importance of a multidisciplinary team. The centrality and reliance on general practitioners to plan and manage care under the CDM item numbers does not recognise the expertise of other groups, such as allied health professionals and nurses, as expert case managers and care coordinators.
- Funding models and Medicare rebates must support innovative service models, such as telehealth. In rural areas it is important that telehealth is not simply viewed as a consumer interacting with a computer, or traditional services delivered remotely. Telehealth models should support multidisciplinary consultations with local clinicians (beyond medicine) funded to participate in telehealth /local based management (eg. in the case of a psychiatrist located at a distant site, and a consumer supported by a local clinician who will be responsible for local care), and novel ways of complementing local services (e.g., consumer coaching).

3. *Opportunities for the Primary Health Networks to coordinate and support chronic disease prevention and management in primary health care:*

- Given major issues of probity, the Primary Health Networks (PHN) must be planners and commissioners of healthcare, and not service providers. In cases where there are service gaps, the PHNs should not duplicate or replicate services that are available in other locations, but must commission and coordinate service providers to fill these gaps.
- There must be transparent and publicly available reporting on the outcomes of

PHNs, with organisations, such as the National Health Performance Authority, charged with external review of PHN performance

4. *The role of private health insurers in chronic disease prevention and management:*

- Whilst there is evidence that rates of private health insurance are lower in rural areas, particularly amongst populations who are vulnerable, there is capacity for private health insurers to continue to expand their work in health promotion.

5. *The role of State and Territory Governments in chronic disease prevention and management:*

- State and Territory Governments must be important players in a multi-sectoral approach to service integration given their roles in funding acute services. Evident in our work is inadequate connections between the acute and primary health sectors.

6. *Innovative models which incentivise access, quality and efficiency in chronic disease prevention and management:*

- One of the biggest risks to improvements in current management of people with chronic conditions (particularly those from vulnerable groups) is a proliferation of innovative models that incentivize access, quality and efficiency. What is needed is a planned and systematic approach to longer term planning, rather than piecemeal funding of innovation for innovation sake.
- There must be strong consumer and carer input into the development of innovative models. What might appear innovative to a group of health professionals or service planners may be inappropriate or unworkable from a consumer/carer perspective.

7. *Best practice of multidisciplinary teams in chronic disease management in primary health care and hospitals:*

- There is clearly a need for professional development in all sectors of the primary health system. Primary health should be viewed in its broadest sense, and should include community wide education: e.g., education providers, emergency services.
- For multidisciplinary teams to function effectively, funding models must be designed to support true multidisciplinary practice, irrespective of geographic location.

8. *Models of chronic disease prevention and management in primary health care that improve outcomes for high end frequent users of medical and health services:.*

- Population groups, such as those with mental illness and/or intellectual and developmental disability who are high users of medical and health services should be prioritised for specific action.

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