

**Submission
No 208**

**INQUIRY INTO HEALTH OUTCOMES AND ACCESS TO
HEALTH AND HOSPITAL SERVICES IN RURAL,
REGIONAL AND REMOTE NEW SOUTH WALES**

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Eating Disorders Rural Access Gap

Introduction:

I am a rural dietitian who lives and works in Coffs Harbour, NSW. I work across a variety of roles including private practice, NSW Health and The University of Newcastle Department of Rural Health. Over the past ten years I have developed high level skills in the provision of evidenced based practice and care for clients with eating disorders in my community.

Through my work, I mentor dietitian colleagues and tutor dietitian students in relation to eating disorder health access and nutrition care.

I have ongoing concerns relating to equitable access to eating disorder services in rural, regional, and remote NSW including service availability, barriers to access and quality of service. I believe the 'access gap' results in poor patient experience, late presentation and unsatisfactory care in rural, regional, and remote NSW compared to metropolitan NSW.

Problem:

An access gap currently exists between services for people with very early stages of an eating disorder that can be managed with specialised community-based preventative programs, people with moderate, but preventable eating disorder symptoms that can be treated in the outpatient or community setting and, services targeting intensive treatment of the disease in the fully developed and highly dangerous stage. It is estimated over 16,825 (16%) people in Coffs Harbour, Nambucca and Bellingen Local government areas have an eating disorder (Australian Bureau of Statistics, 2016; National Eating Disorders Collaboration, 2020).

The problem faced by people living in Coffs Harbour and surrounds can be summarised as having:

- No specific eating disorder inpatient treatment program for people over 16 years
- No day program/ intensive outpatient service

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- Limited specialised preventative, health maintenance and community supports.

These issues can be best explained through the following case study. It is an example of the inequity of the rural health care system opposed to a metropolitan model which I have encountered throughout my work as a rural health practitioner. Whilst this case presents one example, I have many similar recounts of patient experiences when trying to access appropriate and timely treatment for eating disorder diagnoses.

I recently received a phone call from a mother, Pam*, whose 16-year-old daughter Lucy* had been admitted to Coffs Harbour Hospital with a diagnosis of Anorexia Nervosa, a serious mental health disorder. She had phoned me to ask if I would be happy to support Lucy after her inpatient admission.

Pam, a health professional, with a high level of health literacy, recounted her frightening experience of trying to access appropriate support in Coffs Harbour. She described inconsistent advice by health professionals regarding appropriate care pathways, information, and support for her daughter. As Lucy's advocate, Pam sought prompt treatment by the family general practitioner (GP) when she started to notice Lucy's changed eating behaviours. The GP was able to refer Lucy to see a private psychologist and dietitian under the Medicare Eating Disorder Care Plan.

Unfortunately, over the next 6 months Lucy's condition deteriorated, she lost more weight, and had trouble mustering enough energy to complete daily activities. Pam recounted a lack of therapy plan, and no direction towards recovery. Pam was told that Lucy would not be able to receive more intensive treatment for her condition until she became medically unstable (including symptoms of: bradycardia, hypotension, hypothermia, hypoglycaemia, deranged electrolytes and/or irregular cardiac rhythm) or suicidal, only then, would she be able to seek an inpatient admission at Coffs Harbour Hospital. Outside of a metropolitan centre there is currently no option for evidenced based day-programs or specialised eating disorder inpatient treatment programs. Lucy's only option was shopping around for

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incongruent community treatment appointments (private or public), failing that, an inpatient stay on a non-specific and inappropriate hospital ward for medical stabilisation.

Scared and frustrated by this situation, Pam sought the advice of another GP who had been recommended by Lucy's psychologist as someone with eating disorder experience. Despite better direction, Lucy continued to lose weight and became medically unstable with hypotension, hypothermia, and bradycardia. Lucy's mental health declined, she became withdrawn and disinterested in things that used to give her pleasure. Her school marks, which were previously exceptional, also suffered.

Finally, after months of failed community therapy Pam took Lucy to Coffs Harbour Base Hospital Emergency department with serious concerns for her physical health. Pam described a frightening realisation of the inadequacy of the health system when the triage nurse said to her *'You should take Lucy to John Hunter, you'll get better care there, don't come here.'* Pam and Lucy's experience only worsened when told that Lucy (aged 16 years and 3 months) would have to be admitted to the medical ward, a busy adult ward with mainly elderly people. After much campaigning by Pam, Lucy was able to be admitted to the paediatric ward under an adult cardiologist, who indicated they had no training in eating disorder care.

On a positive note, Lucy is currently doing well as an inpatient, she has received a tailored treatment plan and is on her way to recovery. This is a result of collaboration between public and private clinicians, a coordinated plan from the Mid North Coast Eating Disorder Coordinators and the implementation of the new Paediatric and Adolescent Eating Disorder Inpatient Procedure. During her inpatient stay, Lucy has been in regular contact with the inpatient dietitian and the Child and Adolescent Mental Health team. Pam, even though having to navigate this journey alone, is starting to comprehend how the road to recovery is shaped.

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This is as far as Lucy and Pam's story goes to date. I will begin to care for Lucy post admission and look forward to sharing her journey of recovery. Whilst I hope I can help Lucy and Pam; I have limited resources as a private practitioner. Instead of having a gold-standard specialised team under one roof, I will need to contact and collaborate with Lucy's other providers via letter and telephone. Lucy will have some access to mental health support and an adult generalist psychiatrist, but not a specialised eating disorder team. Lucy's journey as a rural patient is not straight forward like her metro counterparts, it is bumpy, undefined, and disjointed.

If Lucy's condition had continued to deteriorate, she may have been deemed 'sick enough' by the system to be transferred to a metropolitan service, 600km away from her family, friends and supports. She would have likely been waitlisted along with other adult patients (>16 years) from around the state who were suffering in similar circumstances. I hope for Lucy, this doesn't have to happen.

This story does not aim to discredit the caring, professional, and highly knowledgeable hospital staff or individual health practitioners, instead it aims to highlight the inequity of the rural health care system opposed to a metropolitan model. Currently, private and public clinicians collaborate to coordinate the best patient care that they can, with the limited resources and funding that they have.

Evidence shows that prompt and systematic treatment for Anorexia Nervosa is the best indicator for recovery (Treasure & Russell, 2011). If Lucy and Pam had lived in Sydney, they would have had easy access to preventative community programs, specialised day-programs, and inpatient programs, for prompt treatment and a clear path forward. I believe improved access and availability to these quality specialised and specific services is vital for prompt and efficient care for our vulnerable young people in rural, regional, and remote settings. By closing the 'access gap' we can improve vulnerable young person mental health care experiences in rural, regional, and remote NSW and align best -practice care models with metropolitan NSW.

Recommendations:

It is recommended that the development of the following services be considered to support the people with eating disorders that live outside of metropolitan NSW.

- A local early intervention/prevention program which aims to support patients and clinicians when the first signs of an eating disorder occur.
- A local intensive day program to support people that have been identified for increased intervention, with specialised medical and allied health staffing.
- That a specific eating disorder inpatient treatment program, with specialised and dedicated staffing, be available for *all* people living rurally and remotely so they can continue to leverage their social supports in an area they are familiar with.
- That a clear care plan which continues to involve collaboration of public and private services, and includes care progressions, is available for all people (rural and remote), including those from minority groups including Aboriginal and Torres Strait Islander peoples, refugee and migrant people, people with a disability, those with co-morbid mental health conditions and those with low health literacy levels.
- Ongoing upskilling or mentoring services available for all health professionals who link in to support the services
- That telehealth services from metropolitan areas are not seen as the solution to these issues, as they do not consider the nuances and contexts faced by rural and remote people.

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National Eating Disorders Collaboration. (2020). Eating Disorders in Australia. Retrieved from <https://www.nedc.com.au/eating-disorders/eating-disorders-explained/something/eating-disorders-in-australia/>

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