

Submission

No 4

**INQUIRY INTO HEALTH CARE COMPLAINTS AND COMPLAINTS  
HANDLING IN NSW**

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**Date Received:** 3/02/2012

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3 February 2012

Committee on the Health Care Complaints Commission  
Parliament House  
Macquarie St  
Sydney NSW 2000

### **Submission to Inquiry into Health Care Complaints Handling in NSW**

Carers NSW welcomes the opportunity to provide comment to the Joint Parliamentary Committee Inquiry on the Health Care Complaints and Complaints Handling in NSW. Our submission will focus on carers' understanding and awareness of the complaint handling mechanisms of the Health Care Complaints Commission (HCCC). Background information about the experiences of regional and metropolitan carers, and the people for whom they care, will also be provided to inform the Inquiry's investigation into complaints made by these groups.

#### **1. About Carers NSW**

Carers NSW is the peak organisation for carers in NSW. It is a member of the national Network of Carers Associations and has an exclusive focus on supporting and advocating for all carers in the state.

Carers NSW vision is that caring is accepted as a shared community responsibility and that all carers in NSW are recognised, valued and supported by their communities and by governments. The goal of Carers NSW is for carers in NSW to have improved opportunities and access to services that meet their needs regardless of their age, gender, circumstances, location or cultural and linguistic backgrounds.

Carers NSW is a member of the Health Care Complaints Commissions' Consumer Consultative Forum and represents the views of carers at quarterly meetings.

#### **2. About Carers**

Carers NSW defines a carer as any individual who provides unpaid care and support to a family member or friend who has a disability, mental illness, drug and alcohol dependencies, chronic condition, terminal illness or who is frail. Carers come from all walks of life, cultural backgrounds and age groups. For many caring is a 24 hour job that is often emotionally, physically and financially stressful.

According to the ABS there are 850,000 carers in NSW, representing 12 per cent of the population, and 264,300 people are classified as primary carers and provide the majority of assistance to the person in their care.<sup>1</sup> Fifty-five per cent of all carers in Australia are women and 67.8 per cent of primary carers are women.<sup>2</sup>

Carers are often personal advocates for the friends and family members they support. HCCC annual report case studies show that people in a caring role have issued complaints to the HCCC on behalf of family members and friends in cases where the patient is unable to make the complaint.<sup>3</sup>

### **3. Carer awareness of the HCCC complaints process**

Information about the HCCC, including its role in processing complaints about health and aged care services is available from Carers NSW. Carers NSW refers carers to the HCCC if they have experienced improper or substandard treatment from health professionals. Carers NSW endeavours to make information about how to make a complaint accessible to all carers and is available both on our website or by calling the Carer Line. The Carer Line also provides carers with information, emotional support, planning and referrals to available services.

A link to the HCCC website and the HCCC inquiry line number are also provided on the Carer Life Course website. The Carer Life Course website features a link to the Carer Life Course e-tool and supporting information for carers. The e-tool has been designed to support carers at each stage of their caring journey from initial awareness that something is wrong with their friend or family member to the end of their caring role.

Carers NSW has not received any feedback from carers, either positive or negative, about the HCCC complaints process. However, from complaints that have been processed by the HCCC it is clear that people acting in a caring role have been calling the HCCC inquiry line and making complaints about the health care of their friends and family members. Case studies provided in the HCCC 2010-11 Annual Report outline scenarios in which family members and friends have issued complaints on behalf of people they have been caring for. For example, one case study featured a husband who made a complaint to HCCC about his wife being transported over long distances between different health facilities in the final month of her life.<sup>4</sup>

While Carers NSW refers carers to the HCCC if they are seeking to make a complaint, it should be noted that there are many carers who do not access services and may not be aware of the health care complaints handling process in NSW. These carers, called “hidden” carers, often do not access support services due to marginalisation or social isolation.

Indigenous carers and carers from culturally and linguistically diverse (CALD) backgrounds are more likely not to access mainstream services and to be considered hidden carers. Caring responsibilities in these communities may be shared across generations leading to no single person identifying as a carer, and caring is viewed as a responsibility to be managed by the whole family or community. Cultural and language differences between patients, their carers and health workers can impact upon the use of services. Recent research from Queensland has shown that people from established CALD communities are unfamiliar with health systems and experience difficulties accessing health care.<sup>5</sup> Similarly,

hidden carers' awareness of complaints mechanisms, and the HCCC, may be limited due to a poor basic understanding of available services and supports.

Carers NSW is aware that the HCCC publishes information, including the complaints form, in community languages and has interpretation services available to help people through the complaints process. Interpretation services and the provision of information in languages other than English help to make the complaints process accessible to all members of the community, however these services do not address a lack of awareness about the HCCC in culturally diverse communities. Carers NSW is pleased that the HCCC has been increasing its engagement with Aboriginal Communities, including through outreach to Aboriginal Health Workers.<sup>6</sup> A similar focus on connecting with CALD communities may help to improve awareness about health complaints handling in NSW.

To increase awareness of the complaints process, information should be provided to service providers, patients and carers in community languages, in addition to the complaint form. Carers NSW recommends that promotional material about the HCCC be published in community languages and distributed to GP clinics, residential aged care facilities, dental surgeries and other appropriate health services. Allowing service providers to nominate the most common languages in their area and order brochures accordingly would ensure targeted and effective promotion of the HCCC.

**Recommendation:** Carers NSW recommends that promotional material about the HCCC and the complaints handling process be made available in community languages.

#### **4. Carers in Metropolitan and Regional Areas**

Carers NSW would like to provide comment in relation to Committee's undertaking of a comparative analysis of the complaints made by people living in metropolitan and regional areas. Carers NSW does not have any specific information on carers we have referred to the HCCC or the outcome of their complaints, however we can provide general information on the experiences of carers living in regional and urban areas.

Carers in rural and regional areas, when compared to carers in metropolitan areas, have a different experience of the health care system. Carers, and the people they care for, in metropolitan areas have better access to services than carers in regional areas. There are more health services in metropolitan areas, resulting in greater choice and there is easier access to public transport.

Carers living in regional areas identify a lack of transport and local services as a main concern. Carers often need to travel vast distances to access the health services in regional centres due to the absence of local health services. Australia wide, 45.3 per cent of carers in outer regional and rural areas have difficulty accessing services, compared to 29.4 per cent in inner regional areas and 25.7 per cent in urban areas.<sup>7</sup> Almost 40 per cent of carers in remote areas named distance as the main reason for not being able to access services, compared to 17.1 per cent of carers in urban areas.<sup>8</sup> Transport issues have been raised in complaints made to the HCCC, such as the case mentioned above in section 3.

For carers and patients relying on public transport, travelling to medical appointments can be even more difficult. There have been situations where carers and patients need to leave two

hours before an appointment due to the unreliability of local bus services.<sup>9</sup> The *2010 Carers NSW Carer Survey* found that 79 per cent of carers living in rural areas identified transport costs as an additional financial burden, compared to 57.9 per cent of carers in metropolitan areas.<sup>10</sup>

Carers in regional areas also have lower incomes than people with caring responsibilities living in metropolitan areas, placing additional pressure on carers. Australia wide, carers in regional areas are slightly more likely to be living in a jobless household (21 per cent) than carers living in major cities (17 per cent).<sup>11</sup> The *2010 Carers NSW Carer Survey* found that 53 per cent of regional carers have household incomes of less than \$700 per week, compared to 36 per cent of carers living in metropolitan areas.<sup>12</sup>

Carers NSW hopes that the above discussion outlining the greater difficulties faced by carers in regional areas will help inform the comparative analysis of complaints. Lower incomes and poorer access to transport and services make caring for someone who is ill, frail aged or disabled much harder in regional areas. Carers NSW is interested to see if the experience of regional carers is reflected in higher rates of complaints to the HCCC from people living in regional areas.

## Conclusion

Carers NSW thanks the Joint Parliamentary Committee on the Health Care Complaints Commission for the opportunity to provide comment on complaints handling mechanisms in NSW. We hope that the information helps to inform the inquiry and improve the health care complaints handling mechanisms in NSW.

For further information regarding this submission, please contact Diana Withnall, Policy and Development Officer, on 9280 4744 or [dianaw@carersnsw.asn.au](mailto:dianaw@carersnsw.asn.au).

Yours sincerely,



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<sup>1</sup> Australian Bureau of Statistics, "Survey of Disability, Ageing and Carers 2009", Canberra, 2010

<sup>2</sup> Ibid.

<sup>3</sup> Health Care Complaints Commission, "2010-11 Annual Report", Sydney, 2011

<sup>4</sup> Ibid, page 35.

<sup>5</sup> S. Henderson and E. Kendall, "Culturally and linguistically diverse peoples' knowledge of accessibility and utilisation of health services: exploring the need for improvement in health service delivery" *Australian Journal of Primary Health*, 2011 17(2):195-201

<sup>6</sup> Health Care Complaints Commission, "2010-11 Annual Report", Sydney, 2011

<sup>7</sup> B. Edwards, M. Gray, J. Baxter, H. Boyd, "Tyranny of Distance: Carers in Regional and Remote Areas of Australia," *Australian Institute of Family Studies*, Canberra, 2009 p.12

<sup>8</sup> Ibid.

<sup>9</sup> T. Jowsey, L. Yen, C. Aspin, N.J. Ward and the SCIPPS Team, "People I can call on: Aboriginal and Torres Strait Islander experiences of chronic illness. Community Report", *Serious and Continuing Illness Policy and Practice Study*, Menzies Centre for Health Policy, Canberra, 2011 p. 25

<sup>10</sup> Carers NSW, "Carers NSW 2010 Carer Survey", Sydney, 2010

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<sup>11</sup> B. Edwards, M. Gray, J. Baxter, H. Boyd, "Tyranny of Distance: Carers in Regional and Remote Areas of Australia. Australian Institute of Family Studies, Canberra, 2009 p. 20

<sup>12</sup> Carers NSW, "Carers NSW 2010 Carer Survey", Sydney, 2010