

**INQUIRY INTO SERVICE COORDINATION IN
COMMUNITIES WITH HIGH SOCIAL NEEDS**

Organisation: Carers NSW

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The Director
Standing Committee on Social Issues
Parliament House
Macquarie St
Sydney NSW 2000

Re: Inquiry into service coordination in communities with high social needs

Carers NSW would like to thank the Committee for the opportunity to submit to this Inquiry. This submission will briefly address key items within the terms of reference highlighting considerations for carers in communities with high social needs. This submission will draw upon our experience as a not-for-profit, non-government provider of services to carers across NSW to highlight key elements of best practice in coordination of services in communities with high social needs.

About Carers NSW

Carers NSW is a not for profit registered charity and company limited by guarantee. It is governed by a Board of Directors in accordance with the *Corporations Act 2001* and the *Australian Charities and Not-for-profits Commission Act 2012*. Carers NSW vision is for an Australia that values and supports all carers, and our goals are to work with carers to improve their health, wellbeing, resilience and financial security; and to have caring recognised as a shared responsibility of family, community, and government.

Carers are over-represented in communities with high social needs

Carers provide unpaid care and support to their family member or friend who has a disability, mental illness, drug and/or alcohol dependency, chronic condition, terminal illness or who is frail. Across NSW there are 857,200 carers (12 per cent of the NSW population), and carers are contributing more hours of care than ever before – with two in five primary carers in Australia spending 40 hours or more per week caring.ⁱ Aboriginal and Torres Strait Islander people are more likely to take on a caring role, and a greater proportion of Aboriginal people are carers compared to the proportion of carers in the whole NSW population.ⁱⁱ

Despite their essential contribution to our communities, carers are a socially disadvantaged group who are more likely to be living in communities with high social needs. When Australians take on a caring role they are likely to face significant financial hardship, as well as challenges to their mental and physical health.

Income is a particularly useful indicator of social needs, and ‘a central factor in shaping individual and family life opportunities’ⁱⁱⁱ. It is therefore important to note that nearly 40 per cent of carers in NSW live in low income households, and nearly 40 per cent receive their main income from a Government pension or allowance. The median weekly income for carers in NSW is also \$100 lower than for the total NSW population. Almost half of the carers in NSW are not in the workforce, and those who are employed are more likely than non-carers to be working part-time.^{iv} The disadvantage experienced within Aboriginal communities is also well documented, and Aboriginal carers are even more likely to be unemployed and have lower incomes than non-Indigenous carers.^v

Carers living in communities with high social needs are likely to be caring for someone who is also on a low income. Data from the 2009 Household, Income and Labour Dynamics in Australia (HILDA) Survey has revealed that carers living in a household with someone else who was receiving a Centrelink payment were severely financially stressed. Just under a third reported not being able to pay electricity, gas or telephone bills on time because of a shortage of money, more than half had to seek financial assistance from family and friends and almost a third had to approach welfare or community agencies for help.^{vi}

It is also well established that carers are more likely than non-carers to experience reduced physical, mental and emotional health. Australian studies have demonstrated that carers are 40 per cent more likely to suffer from at least one chronic health condition when compared to the rest of the community. Caring can have a significant impact on carers’ mental health, including increased levels of depression and anxiety. Carers have poorer mental health than other at-risk groups, including the unemployed, and a major study conducted in 2007 revealed that over half had a rating on the Depression Anxiety and Stress Scales (DASS) consistent with at least moderate depression.^{vii}

Carers are more likely to report high blood pressure, high cholesterol, be categorised as overweight or obese, and are more likely to be experiencing chronic pain or carrying an injury associated with caring.^{viii} Carers are also more likely to have a disability themselves^{ix}, and it is estimated that Aboriginal and Torres Strait Islander carers are between 1.5- 3 times more likely to have a disability.^x

In light of the challenges associated with having a caring role, it is critical that support for carers is embedded in any approaches to addressing the needs of communities with high social needs.

Carers’ experiences of services

Carers provide care to people experiencing a wide variety of conditions, and they often find themselves navigating between different service systems alongside the person they care for, including hospitals, GPs and mental health services, Centrelink and job network agencies, housing agencies, aged care, disability services, child and family services, and courts and legal services. Responsibility for these services lies in a complex web of local, state, federal Government and non-government providers, and Carers NSW often hears from carers who are lost in a service maze. Often it is carers who are left to take on the role of care coordinators and advocates for their loved ones, as services which offer case management and case coordination are unavailable. A coordinated response to the needs of carers and their families is urgently needed.

Carers' experience of mental health services

It is well known that the mental health system is complex, fractured and difficult for consumers and carers to navigate. Carers frequently report to Carers NSW that transitions between hospital and community settings are particularly poorly co-ordinated. A lack of communication and continuity of care between services is detrimental to consumers' recovery journey and results in significant gaps in support.

These gaps can result in significant strain on the carer/s who frequently struggle to find adequate services to support their loved one. The words of one carer we spoke to are typical- 'I was not given any information regarding his condition and simply had to wait for the next psychotic episode to occur and call the Crisis Team.'

Barriers to service coordination

Carers NSW is committed to working in partnership with a range of providers in order to deliver coordinated responses to carers and the people they care for, however the complexity of health and social care systems can be just as bewildering to service providers as it is to service users. Referring to health services, Salvador-Carulla et. al note:

'The need for simple rules of navigation is strong, but fragmentation and gaps in services remain great, confounding attempts to understand and organise appropriate care and support.'^{xi}

The lack of clarity around which organisations receive funding and to which purpose, represents a significant barrier to service coordination.

Another barrier to service coordination is the tendency for carers' support needs to be dealt with separately to the support needs of the people they care for. For example, in focusing on the support needs and goals of participants with disability, the National Disability Insurance Scheme (NDIS) does not provide assessment, support planning or funded supports to carers in their own right. Carers' own needs are being addressed separately by the development of an Integrated Plan for Carer Support Services, the first stage of which is the National Carer Gateway, a 1800-number and website with information and support.

While the aim of better centralising information about carer supports is admirable, the segregation of these supports from the disability support, aged care, mental health and community welfare systems

may create further complications for carers, unless referral pathways are very clear and staff in both systems are well trained to connect carers to appropriate services.

Service mapping

The first step towards improving integration and coordination of services is comprehensive service mapping, which allows all stakeholders to see how communities with high social needs are currently being serviced. Service mapping allows government and non-government agencies to understand the service landscape, and highlight what is working, and where there are service gaps.

‘Service mapping...is an established means of understanding the service system in order to improve coordination and integrate service delivery for improved client outcomes.’

Homelessness Service System Mapping NSW Summary Report (2012)

‘Integrated Atlases allow policy planners and decision makers to understand the landscape in which they work (including areas of gap or over-supply), make bridges between the different sectors and to better allocate services. This is particularly important as... public investment focuses on person-centred care coordination programs such as Partners in Recovery (PIR) or the National Disability Insurance Scheme (NDIS).’

The Integrated Mental Health Atlas of Western Sydney (2015)

Investment in comprehensive service mapping across areas of high social need in NSW, which considers the supports available to carers, will facilitate better coordination of services, allocation of resources, and assist in the identification of gaps in service for carers and the people they care for.

Delivering integrated, coordinated services

Carers and the people they care for living in communities with high social needs are likely to be experiencing challenges across many domains. For this reason services which work together to holistically address the full range of their family’s needs have the best chance of making a real difference to carers’ lives.

Long-term partnerships between government and non-government are crucial to the coordination of services, and these partnerships should facilitate smooth transitions between the service systems that carers in disadvantaged communities are navigating. Integrated service delivery models build the capacity of all sectors to provide support which makes a difference to the lives of carers living in communities with high social needs.

Building relationships in Aboriginal communities

Since 2011 Carers NSW has received funding through Ageing, Disability and Home Care (ADHC), the NSW Department of Family & Community Services (FACS) to deliver the Older Parent Carer Support Coordination Program in locations across NSW, including in Orana and Far West of NSW. Orana and the Far West have a high concentration of localities which have been identified as some of the most extremely disadvantaged in NSW, and there is a significant Aboriginal and Torres Strait Islander population in these areas.

The aim of the Older Parent Carer (OPC) Program is to help carers prevent or alleviate the stress that can build up within a family due to the caring role. Support Coordinators build on the strengths of families to connect them to social networks and the service system, and each support plan is tailored to the particular family situation.

One goal of the OPC program is to reach out to hidden Aboriginal carers, and OPC Support Coordinators in Aboriginal identified positions have had great success in this area. OPC staff attribute this success to the development of strong relationships and partnerships with a range of service providers and carers in local communities, allowing staff to gain the trust of local communities, and word of our services to spread. They report that face-to-face engagement with carers and service providers has the most success, in the words of one Support Coordinator- 'you can't beat it'.

Recently Carers NSW Support Coordinators have partnered with Ability Links, and they have undertaken face-to-face visits together. Carers NSW established position in the community has been beneficial for the newly established Ability Links program, and when carers are not eligible for OPC, Ability Linkers can help them to find other options.

Identifying hidden carers

A key opportunity for better service coordination for carers in high needs communities is identification by staff of mainstream services with which they interact. The challenges experienced by many carers, and the likelihood that disadvantaged people will be supported by carers, means that mainstream services which are frequently used by high needs groups, such as GPs, hospitals and housing agencies,

are also highly likely to be frequented by carers. However, these carers are often 'hidden', in that they do not recognise or disclose their caring role, and are therefore not known as carers to the service system or offered support. Properly trained and resourced staff in these services should be well placed to identify hidden carers. However, services and professionals are often not in a position where they can easily recognise them and/or connect them with appropriate support.

Identifying carers in social housing

Carers NSW is currently undertaking a project in partnership with the Department of Family and Community Services (FACS) to better equip social housing staff to identify and support hidden carers. The project involves basic carer awareness training and training in how to identify and support hidden carers. An accompanying resource assists social housing staff to refer carers directly to the Carer Line (Carer Advisory Service), where Carers NSW staff can provide referral and support based on service need and availability. This project is one example of how mainstream services dealing with high needs communities can be prepared to identify with carers and streamline carer support.

Identifying culturally and linguistically diverse carers

NSW is one of the most culturally diverse communities in Australia, and the 2012 SDAC indicates that about 179 100 carers in NSW are born in a non-main English speaking country, and 114 700 carers in NSW speak a language other than English as their main language at home. Of these, 32 900 do not speak English well; and 1400 don't speak English at all. These carers can be identified as being most affected by cultural and linguistic barriers.

As many CALD carers do not recognise terms such as 'carer' or 'respite', CALD carers are less likely to identify as carers and therefore may not be receiving services to support them in their caring role. Carers from CALD backgrounds may also face additional impacts of the caring role due to cultural issues or language barriers- for example many CALD carers act as health interpreters. Service providers working in communities with high social needs must give consideration to the unique needs of CALD carers.

Carers NSW thanks the Committee for the opportunity to contribute to this inquiry. For further information regarding this submission, please contact Carolina Simpson, Policy and Development Officer, on (02) 9280 4744 or carolinas@carersnsw.org.au.

Yours sincerely,

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ⁱ Australian Bureau of Statistics (2013) *Disability, Ageing and Carers, Summary of Findings, 2012*, Carer tables, Catalogue no. 4430.0.

ⁱⁱ Australian Bureau of Statistics (2011) *Census of Population and Housing*, Table B21, Canberra.

ⁱⁱⁱ Vinson and Rawthorne, (2015) *Dropping off the Edge 2015*, Persistent Communal Disadvantage in Australia, Jesuit Social Services and Catholic Social Services Australia.

^{iv} ABS (2013). Low income is defined as residing in a household with equivalised gross household income in the lowest two quintiles.

^v Australian Bureau of Statistics (2011) *Census of Population and Housing*, Table B21, Canberra.

^{vi} Household Income and Labour Dynamics in Australia Survey (2009) referred to in Carers Australia (2014) *Submission to the Review of Australia's Welfare System*

^{vii} Carers Australia, Australian Unity, and Deakin University (2007) *The Wellbeing of Australians: Carer Health and Wellbeing*, Australian Wellbeing Index Survey 17.1.

^{viii} Ibid.

^{ix} ABS (2013).

^x Australian Institute of Health and Welfare (2011) *The health and welfare of Australia's Aboriginal and Torres Strait Islander peoples: An Overview*, Canberra.

^{xi} Salvador-Carulla, L., Fernandez, A., Feng, X., Astell-Burt, T., Maas, C., Smith-Merry, J., Gillespie, J. (2015). *The Integrated Mental Health Atlas of Western Sydney*, Draft for comments. Mental Health Policy Unit, Brain and Main Research Institute, Faculty of Health Sciences, University of Sydney. Western Sydney Partners in Recovery, Sydney.