

# Royal Commission into Aged Care Quality and Safety

NCOSS Submission



September 2019

# About NCOSS

The NSW Council of Social Service (NCOSS) works with and for people experiencing poverty and disadvantage to see positive change in our communities.

When rates of poverty and inequality are low, everyone in NSW benefits. With 80 years of knowledge and experience informing our vision, NCOSS is uniquely placed to bring together civil society to work with government and business to ensure communities in NSW are strong for everyone.

As the peak body for health and community services in NSW we support the sector to deliver innovative services that grow and evolve as needs and circumstances change.

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## Introduction

This Royal Commission comes at a time when the aged care and community sector across Australia is undergoing significant reform and upheaval, as governments transition from direct service provision to the purchasing of services from non-government and community-based organisations. This change shifts greater responsibility and risk to the community sector. The move to consumer-driven care and individualised funding packages, data driven decision-making, and commissioning for outcomes are some of the changes that the sector is grappling with in a constantly evolving and complex landscape.

In this context, NCOSS believes it is best placed to respond to Terms of Reference (c) and (d), with specific regard to challenges around service access, sustainability and responsiveness to diverse needs, including for older people in regional communities.

Over the last few years NCOSS has undertaken grassroots consultation in over 24 communities across metropolitan and regional NSW and regularly convened a range of expert advisory groups – including the Forum of Non-Government Agencies, Regional Forum, Health Equity Alliance and Children, Young People and Families Alliance. NCOSS is also a member of the NSW Ageing Alliance and in 2017 held a roundtable of members and stakeholders to discuss barriers to social connection for older people in marginalised communities.

This submission is therefore informed by the expertise and experiences of our members, expert advisory groups, the broader social services sector and their clients. NCOSS also acknowledges and endorses evidence already provided to the Royal Commission from other peak bodies including Council on the Ageing, Dementia Australia and ACON.

## Recommendations

1. Improve accessibility of My Aged Care and the broader aged care system for older people from diverse communities, including regional, Aboriginal and Torres Strait Islander, and culturally and linguistically diverse communities.
2. Retain a funding model for Commonwealth Home Support Program services, including social support and community transport, that enables flexible responses to diverse needs and initiatives that benefit the whole community.
3. Directly fund the aged care and community sector to provide social inclusion programs and initiatives.
4. Ensure carer support, resources and respite are adequately funded in recognition of the ageing population and growing demand.

# Barriers to accessing aged care

## Challenges with My Aged Care

There is evidence to suggest that My Aged Care is failing to provide older people and their carers with an effective gateway to a range of aged care options. What was intended as an accessible single entry point has instead become a bottleneck for older people with increasingly complex needs.

The latest Home Care Packages Program (HCPP) data report shows that as of 30 June 2019, there were 72,062 people who were waiting for a home care package at their approved level, who had not yet been offered a home care package. Over 11,000 of these are people with high-level care needs who face a wait time of over 12 months to receive their package,<sup>1</sup> during which time their conditions are likely to deteriorate significantly without the right support.

Further, the My Aged Care website is not easy to access for older people who are not comfortable or familiar with technology, or are members of Aboriginal and Torres Strait Islander or culturally and linguistically diverse (CALD) communities. Between 2015-17 Partners in Culturally Appropriate Care NSW & Act consulted CALD communities on My Aged Care and found that:

- There remains a low level of awareness about My Aged Care.
- There are a number of systemic service access barriers for CALD consumers and their communities, including:
  - Language and literacy barriers, including a lack of translated information;
  - Low understanding of the aged care system
  - Limited access to and the suitability of online and telephone access service channels;
  - Complexity of assessment processes;
  - Trust issues in having to reveal highly personal information to ‘strangers’ multiple times;
  - Low levels of cultural competence in services.<sup>2</sup>

All these factors present a real barrier to a diversity of older people accessing a range of information and services.

Sometimes the most significant barrier to older people from marginalised communities accessing supports is the perception that services are not welcoming or culturally safe. They may often feel most comfortable talking about their situation with someone in their community.<sup>3</sup> A lifelong distrust of government services can mean that people might minimise their needs when interacting with someone outside their community, and not get enough support to meet their needs.

My Aged Care and the broader aged care system must be accessible to older people from diverse communities, including regional, Aboriginal and Torres Strait Islander, and culturally and linguistically diverse communities. This should include:

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<sup>1</sup> Department of Health 2019, *Home Care Packages Program: Data Report 4<sup>th</sup> Quarter 2018-19*, Australian Government, September, available at: [https://www.gen-agedcaredata.gov.au/www\\_aihngen/media/Home\\_care\\_report/HCPP-Data-Report-4th-qtr-2018-19.pdf](https://www.gen-agedcaredata.gov.au/www_aihngen/media/Home_care_report/HCPP-Data-Report-4th-qtr-2018-19.pdf)

<sup>2</sup> Partners in Culturally Appropriate Care NSW & Act 2017, *CALD MAC Accessibility Project: Barriers and recommendations for CALD persons 65+ when accessing My Aged Care consumer pathway*, Multicultural Communities Council of Illawarra Inc, Sydney.

<sup>3</sup> NCOSS 2017, *Increasing social connection for older people in marginalised communities*, June, available at: <https://www.ncoss.org.au/news-and-events/ncoss-news/scoping-paper-explores-options-for-increasing-social-connection-for-older>

- Developing linkage services to provide information and facilitate entry into the aged care system for older people from diverse communities. These services should be block funded and delivered at a local level by organisations with proven experience in working with diverse communities;
- Testing additional and face-to-face supports to assist older people from diverse communities and their carers entering and navigating the aged care system, including supported referrals to My Aged Care (for example COTA's Aged Care System Navigators Pilot project);
- Providing additional funding for specific information sessions to older people from diverse communities and their carers;
- Ensuring the viability of the necessary specialist and culturally appropriate services for diverse and regional communities.

### Challenges for regional communities

For many older people, lack of transport is a major barrier to accessing health services, especially older people in rural and regional areas, those on lower incomes, and socially isolated older people. Regional communities already face a lack of specialist health care services,<sup>4</sup> and lack of transport can further reduce the likelihood that older people will be connected to their community and access preventative health care, obtain early diagnoses and access effective care and supports.<sup>5</sup> This is where the community transport (CT) sector, partly funded under the Commonwealth Home Support Program (CHSP), does what they can to fill the gap and are heavily relied upon by regional communities.

However, a real concern for CT providers is funding uncertainty under the CHSP from mid-2022 and what this means for block funding and service sustainability. CT providers are concerned they would not be able to deliver the same flexible, cost-effective services under an individualised funding model, where funding allocations are unlikely to reflect the true cost of delivery particularly in regional areas.

This is already playing out under the National Disability Insurance Scheme (NDIS). Insufficient funds for community transport in NDIS plans<sup>6</sup> mean that charging people the full gap of their travel costs may exclude them from accessing transport at all, particularly if they live in areas where distances are long. The latest NDS State of the Disability Sector Report already indicates that 15 per cent of service providers will need to reduce or cease their provision of transport assistance.<sup>7</sup>

Any changes to community transport funding under the CHSP must ensure to support responsive and flexible community transport options in regional and remote areas, to facilitate more access to services for older people.

<sup>4</sup> Australian Institute of Health and Welfare 2017, *Rural and Remote Health*, Canberra, available at: <https://www.aihw.gov.au/reports/rural-health/rural-remote-health/contents/rural-health>

<sup>5</sup> Corcoran, K., McNab, J., Girgis, S. & Colagiuri, R. 2012, 'Is transport a barrier to healthcare for older people with chronic diseases?', *Asia Pacific Journal of Health Management*, Vol. 7, No. 1, Jun 2012, pp. 49-56.

<sup>6</sup> NDS 2018, *Essential Issues Paper: Getting Transport on Track*, available at: [https://www.nds.org.au/images/files/Essential\\_Issues-Getting\\_transport\\_on\\_track\\_May\\_2018.pdf](https://www.nds.org.au/images/files/Essential_Issues-Getting_transport_on_track_May_2018.pdf)

<sup>7</sup> NDS 2018, *State of the Disability Sector Report 2018*, available at: <https://www.nds.org.au/news/state-of-the-disability-sector-report-2018-now-available>

# Supporting people in the community

## Social inclusion and support

While ageing is not a precursor to experiencing social isolation, it is clear that keeping older people connected and supported in their own home and community plays a key role in their overall wellbeing.

Social isolation and loneliness have been linked to higher risk of poor physical and mental health, including high blood pressure, heart disease, cognitive decline, anxiety and depression.<sup>8</sup> People experiencing loneliness are 60 per cent more likely to use emergency services, while older people experiencing loneliness are twice as likely to be admitted to residential aged care.<sup>9</sup>

In 2014, over a third (37%) of older Australians did not have weekly contact with someone outside their household.<sup>10</sup> This is a sobering figure when we consider that by 2026, the number of older Australians living alone is projected to increase to 39 per cent.<sup>11</sup>

Research identifies key elements that are successful in fostering social inclusion and building social support:

- making use of existing community resources (such as public spaces);
- focusing on quality rather than quantity of relationships;
- using volunteers to run programs;
- utilising (and funding) local councils as a gateway to accessing community services;
- providing meaningful, purposeful activity;
- using targeted and tailored approaches;
- age friendly communities and transport; and
- providing opportunities for active engagement: involving older people in the planning, delivery and evaluation of programs.<sup>12</sup>

Generalist, place-based community services like neighbourhood centres (also known as 'community centres' or 'neighbourhood houses') combine many of these elements to play an important role in social participation and inclusion. Across Australia, almost 8 in 10 (79%) clients of neighbourhood centres are identified as being at risk of social isolation and many are older men and women (42% and 66% respectively).<sup>13</sup>

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<sup>8</sup> National Institute on Aging 2019, *Social isolation, loneliness in older people pose health risks*, U.S. Department of Health & Human Services, April 23, available at: <https://www.nia.nih.gov/news/social-isolation-loneliness-older-people-pose-health-risks>

<sup>9</sup> Franklin, A. & Tranter, B. 2011, 'AHURI Essay Housing, loneliness and health', *Australian Institute of Housing and Urban Research Institute*, AHURI Final Report no. 164, 6.

<sup>10</sup> AIHW 2018, *Older Australia at a glance*, September, available at: <https://www.aihw.gov.au/reports/older-people/older-australia-at-a-glance/contents/healthy-ageing/mental-social-wellbeing>

<sup>11</sup> ABS 2004, *3236.0 Household and Family Projections, Australia, 2001 to 2026*, available at: <https://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/3236.0Main+Features12001%20to%202026>

<sup>12</sup> Aged and Community Services 2015, *Social Isolation and Loneliness Among Older Australians: A Discussion Paper*, available at: <https://www.acsa.asn.au/getattachment/Publications-Submissions/Social-Isolation-and-Loneliness/1015-Social-Isolation-and-Loneliness-Paper.pdf.aspx?lang=en-AU>

<sup>13</sup> Australian Neighbourhood Houses & Centres Association 2011, *Neighbourhood Houses & Centres: Who we are and What we do*, May, available at: <http://www.anhca.asn.au/about-us/neighbourhood-house-centre-report>

The reach of neighbourhood centres is unique and spans across metropolitan, regional and remote areas, with at least one centre located in most federal electorates.<sup>14</sup> This familiarity with and grounding in local community enables them to provide services in a non-threatening environment and serve as soft entry points for people who would otherwise fall through the gaps of the aged care and other systems.

In NSW, the funding program for neighbourhood centres and other services is undergoing reform. This reform is asking services to shift their focus towards children and families at risk of entering the child protection system and away from broader supports for other vulnerable groups (including older people) and diverse needs. Meanwhile, the NSW Government's funding mechanism for social connection, the Liveable Communities Grants Program, wrapped up in 2018 and its future is unclear.

Governments have a responsibility to look after the wellbeing of all its citizens, and not focus on specific cohorts at the expense of others. To ensure social inclusion initiatives work for older people in the community, they need to be sustainable, well-resourced and flexible enough to respond to diverse needs.

### Community Home Support Program

Many social groups for older people are funded under the CHSP as social support groups and are accessible through My Aged Care. The Community Visitors Scheme also supports older people in residential aged care or community care at risk of social isolation.

These are highly valued initiatives, but again face funding uncertainty with the CHSP funding transformation in mid-2022. In addition, the introduction of competitive tendering for Community Visitors Scheme funding in 2018 threatens the long-term stability and viability of services offering this support.

Social isolation in older people requires a response that is community-led, and support that is built on long-standing, trusted relationships. Stability of funding is therefore a crucial part in ensuring services can continue to support social connection.

### Carer support

Informal, unpaid carers play a key role in supporting older people to stay in their own home and community for longer. They also save the aged care system and the economy billions of dollars; a 2015 Deloitte report estimated that replacing all hours of informal care provided that year with purchased formal care services would cost \$60.3 billion.<sup>15</sup>

The personal cost to carers is significant. They generally have poorer health and wellbeing than non-carers, as well as a lower income and standard of living.<sup>16</sup> 56% of primary carers aged 15-64 participate in the workforce, compared to 80% of non-carers.<sup>17</sup> Carers already bear a significant burden before they encounter challenges with the aged care system.

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<sup>14</sup> Ibid.

<sup>15</sup> Deloitte Access Economics 2015, *The economic value of informal care in Australia in 2015*, available at: <https://www.carersaustralia.com.au/storage/access-economics-report3.pdf>

<sup>16</sup> Hughes, J. et al 2007, *The Wellbeing of Australians – Carer Health and Wellbeing*, Australian Unity Wellbeing Index Survey 17.1, Report 17.1, October, Deakin University, Geelong.

<sup>17</sup> ABS 2015, *4430.0 Disability, Ageing and Carers, Australia: Summary of Findings, 2015*, available at: <https://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4430.0Main%20Features12015?opendocument&tabname=Summary&prodno=4430.0&issue=2015&num=&view=>

With more than half of primary carers providing at least 20 hours care a week,<sup>18</sup> respite care should be an important part of the aged care system to enable carers to access much needed time off. However, carers are finding it increasingly difficult to access respite care and other supports, including associated transport needs.<sup>19</sup> There are also concerns that the new Integrated Care Support Services (ICSS) program, due for implementation in October 2019, has not been adequately funded and represents a significant loss in funding for carer support services.<sup>20</sup>

Given the ageing population, the demand for informal care and carer support will continue to grow. Governments need to ensure carers are provided with adequate support, resources and respite to ensure they can continue caring for older people in the community.

## Enabling services to better respond to community needs

As the public sector withdraws from direct service provision, a move towards individualised funding models, while a positive step towards more consumer choice and control, now places the community services sector in a competitive market as block funding is withdrawn. At the same time, the sector is left unfunded to support people who fall through the cracks of individualised funding schemes or are unable to navigate increasingly complex systems.

Many initiatives that support older people in the community face an uncertain future as aged care services transition to being delivered via individualised budgets instead of block funding. While NCOSS supports the choice and control which individualised funding offers consumers, block funding has previously enabled services to pool their resources for initiatives that benefit entire communities in addition to individuals.

Support services for older people may not continue to be viable unless they are funded in a way that allows for flexible responses to diverse needs within the community.

Thank you for the opportunity to contribute to this Royal Commission. We would very much welcome the opportunity to discuss this submission with you in greater depth. Should you have any questions in relation to this matter, please do not hesitate to contact NCOSS Director of Policy & Research, Anna Bacik (02) 8960 7916 or via email at: [anna@ncoss.org.au](mailto:anna@ncoss.org.au).



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<sup>18</sup> Ibid.

<sup>19</sup> Carers Australia 2018, *Improving access to aged residential respite care*, available at: <https://www.carersaustralia.com.au/storage/final-residential-respite-care-report-2.pdf>

<sup>20</sup> Carers Australia 2019, *2019-20 Federal Budget Submission*, available at: <https://www.carersaustralia.com.au/storage/carers-australia-2019-20-federal-budget-submission.pdf>