

23 August 2019

Productivity Commission  
Locked Bag 2, Collins Street East  
Melbourne, VIC 8003

## **Response to the Issues Paper on an Indigenous Evaluation Strategy**

Carers NSW thanks the Productivity Commission for the opportunity to provide a written submission on the Indigenous Evaluation Strategy.

Carers NSW is the peak non-government organisation for carers in NSW. A carer is any individual who provides care and support to a family member or friend who has a disability, mental illness, drug and/or alcohol dependency, chronic condition, terminal illness or who is frail. Our vision is an Australia that values and supports all carers, and our goals are to:

- Be a leading carer organisation in which carers have confidence
- Actively promote carer recognition and support
- Actively support carers to navigate a changing service landscape that will be characterised by ongoing policy reform
- Promote connected community experiences and opportunities for carers that are inclusive of diverse carer groups
- Lead and advocate for carer-specific and carer-inclusive policy making, research and service delivery
- Continue to be a quality-driven, responsive and carer-focused organisation.

This submission focuses on issues surrounding the evaluation of programs benefiting carers in Aboriginal and Torres Strait Islander communities. It draws on available research as well as our experience as a peak organisation and service provider and was developed by the Carers NSW Research Team with input from our Reconciliation Action Plan Working Group and Research and Evaluation Committee.

### **Indigenous carers in NSW**

In 2016 an estimated 20,600 Aboriginal and Torres Strait Islander carers aged 15 years and over were living in New South Wales (NSW).<sup>1</sup> Research suggests that Aboriginal and Torres Strait Islander people are up to twice as likely as other Australians to be carers. The Australian Bureau of Statistics Survey of Disability, Ageing and Carers (SDAC) 2015 identified 2.7 million Australians, or 11% of the population as carers.<sup>2</sup> In comparison, the National Aboriginal and Torres Strait Islander Social Survey 2014-2015 reported 25.5% of Aboriginal and Torres Strait Islander were providing unpaid care. Among Aboriginal and Torres Strait Islander people living remotely, up to 34% were in a caring role.<sup>3</sup>

The higher incidence of caring in Aboriginal and Torres Strait Islander communities is linked to the greater prevalence of disability and chronic health conditions in these communities. Other contributing factors include limited appropriate service options and reluctance to engage in formal services for

<sup>1</sup> Australian Bureau of Statistics (2016a) Census of Population and Housing, Table I09, Canberra: Australian Government.

<sup>2</sup> Australian Bureau of Statistics (2016b) Survey on Disability, Ageing and Carers 2015, Summary of Findings, Canberra: Australian Government.

<sup>3</sup> Australian Bureau of Statistics (2016c) National Aboriginal and Torres Strait Islander Social Survey, Australia, 2014-15, Cat.4714.0, Table 10.3, Canberra: Australian Government.

historical and cultural reasons.<sup>4</sup> At the same time, Aboriginal and Torres Strait Islander carers often have strong connections with their families and communities through kinship systems and view care as a shared family and community responsibility.

Research also indicates that Aboriginal and Torres Strait Islander carers are more likely than other carers to support multiple care recipients. This is particularly true of older Aboriginal and Torres Strait Islander people, who often have multi-generational caring roles.<sup>5</sup> The socio-economic disparities experienced by Aboriginal and Torres Strait Islander communities are well documented. Being a carer can result in additional challenges for Aboriginal and Torres Strait Islander people, including balancing paid work and care.<sup>6</sup>

To improve outcomes for Aboriginal and Torres Strait Islander carers, Carers NSW advocates for engaging Aboriginal and Torres Strait Islander carers in shaping the policies and programs which affect them and ensuring that programs are flexible, holistic and accommodate diverse caring circumstances and historical and cultural factors, as well as supporting existing kinship networks.<sup>7</sup>

### **Challenges in evaluating carer services**

A variety of publicly funded services exist to support carers, including counselling, respite, peer support groups and financial support.<sup>8</sup> These programs vary in eligibility criteria, objectives, scope, availability and delivery models. These diverse characteristics, in combination with the varied approaches to program funding and reporting across sectors and jurisdictions, have prevented uniform evaluation standards from developing.

Beyond administrative complexities, methodological, cultural and ethical considerations pose challenges for devising effective evaluation designs for services benefitting carers. A key methodological challenge lies in measuring the effectiveness of carer support services, given the limited potential for a carer's health and wellbeing to improve while the key 'stressor' – the caring role – remains.

Caring roles can take many forms, vary in intensity, and need to be understood within the scope of the personal relationship between the carer and the care recipient. The caring role is intimately connected with identity, culture, and community specific norms and values. Culturally specific considerations therefore need to play an important part in program and project design, delivery and evaluation.

Ethical considerations also have an impact on the feasibility of evaluation methodologies. In the context of limited funding for carer services for instance, experimental designs such as randomised controlled trials are not only very resource-intensive – requiring resources that could otherwise be used for service delivery – but also predicated on having a control group without intervention, purposefully not being provided a potentially beneficial service. These challenges for the evaluation of carer services in general translate to specific challenges for the evaluation of carer services in Aboriginal and Torres Strait Islander contexts.

In the context of Aboriginal and Torres Strait Islander communities, the caring role is often seen as a natural extension of normal family roles and ultimately a community responsibility. The highly unique

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<sup>4</sup> Australian Institute of Health and Welfare 2017. Aboriginal and Torres Strait Islander Health Performance Framework 2017 report: New South Wales. Cat. No. IHW 182. Canberra.

<sup>5</sup> Carers NSW (2018a) Carers NSW 2018 Carer Survey, North Sydney.

<sup>6</sup> Hunter, B., Gray, M. & Crawford H. (2016) 'Who Cares and Does it Matter for the Labour Market? A Longitudinal Analysis of the Labour Force Status of Indigenous and non-Indigenous Carers', Centre for Aboriginal Economic Policy Research, Canberra: ANU College of Arts & Social Sciences.

<sup>7</sup> Carers NSW (2018b) Policy Statement - Aboriginal and Torres Strait Islander Carers.

<https://www.carersnsw.org.au/Assets/Files/2018-01-15%20Aboriginal%20and%20Torres%20Strait%20Islander%20Carers-%20Policy%20Statement.pdf>

<sup>8</sup> For an overview see Carers NSW (2019): Services & Support webpage, <https://www.carersnsw.org.au/advice/services-supports>

nature of the caring experience renders the entire field – especially in sensitive contexts such as Aboriginal and Torres Strait Islander communities – a challenging environment for standardised evaluative practices. Quantitative outcome measures insensitive to the specificity of circumstances can potentially lead to erroneous conclusions. Evaluation designs in the context of care in Aboriginal and Torres Strait Islander communities need therefore to be based upon methodologies responsive to highly unique circumstances, and also understand caring as a relationship, rather than a service provided to an isolated customer.

With regard to cultural safety, research suggests that the service uptake by Aboriginal and Torres Strait Islander people in the health sector is negatively affected by a lack of cultural safety or cultural appropriateness of service delivery.<sup>9</sup> An evaluation framework for programs working with Aboriginal and Torres Strait Islander people therefore needs to incorporate evaluative elements for guaranteeing cultural safety from the design stage of the program onwards, such as co-design and community consultations. Further, applying the principle of self-determination, evaluative measures in the context of services provided to Aboriginal and Torres Strait Islander people should work toward building relationships of trust and understanding, and ultimately the community taking ownership of the program or policy in question.

Especially against the backdrop of colonial history, experimental approaches and designs which shift significant resources from program delivery to the evaluation of programs may be ethically and culturally problematic in the context of Aboriginal and Torres Strait Islander communities. Such methodologies need to respect the principles of equal access, self-determination and cultural appropriateness, as formulated e.g. in the research guidelines published by the Australian Institute for Aboriginal and Torres Strait Islander Studies.<sup>10</sup>

In light of the above examples, Carers NSW advocates for building an evaluative framework around the principles of self-determination, cultural safety, flexibility, inclusivity, and a holistic apprehension of social situations. This needs to find its expression by taking increasing social and emotional wellbeing of Aboriginal and Torres Strait Islander people as the primary objective of evaluative practices, before considering cost and efficiency aspects.

Such principles encourage approaches to evaluation which involve Aboriginal and Torres Strait Islander participants directly in planning and participatory capacities, and require methodological openness and reflexivity. The methods and measurements applied need to be culturally and ethically sensitive, as well as responsive to the specific social situations of Aboriginal and Torres Strait Islander people.

Thank you once again for accepting our submission. For further information, please contact Dr Lukas Hofstaetter, Research and Development Officer

Yours sincerely,

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<sup>9</sup> AIHW 2018a. Aboriginal and Torres Strait Islander Health Performance report. Cat. No. IHW 194. Canberra: AIHW.

<sup>10</sup> AIATSIS 2012. Guidelines for Ethical Research in Australian Indigenous Studies. <https://aiatsis.gov.au/sites/default/files/docs/research-and-guides/ethics/gerais.pdf>