

Informing emerging carer policy

Carer Knowledge Exchange Research Incubator consultation

Background

The [Carer Knowledge Exchange \(CKE\)](#) is a research translation project led by Carers NSW and funded by the NSW Government that aims to improve outcomes for family and friend carers across Australia by connecting research to practice.

In Phase 1 of the project (July 2021 to June 2024), Carers NSW partnered with the Institute for Public Policy and Governance (IPPG) at the University of Technology Sydney to deliver regular events, including an annual online Research Incubator event held over multiple sessions.

About this paper

This paper outlines the key themes arising from an interactive consultation session held as part of the 2024 Research Incubator, 'Sustainability and carers'. The session, facilitated by Carers NSW CEO Elena Katrakis, was entitled 'Informing emerging carer policy' and was held on Thursday 30 May 2024.

There were 30 attendees, who were each invited to contribute their feedback to a number of discussion questions via Mentimeter and in breakout room discussion groups. Most (70%) attendees identified as current or former carers, with other participants bringing carer-focused research, policy and practice perspectives.

At the beginning of the session, participants were asked to rate their top policy priorities for carers from a pre-prepared list. The highest rated policy areas were:

1. Carer rights and recognition
2. Financial support and longer term financial security
3. Employment rights and entitlements for carers
4. Access to carer support services including respite
5. How the term "carer" is used and defined

The key themes emerging from participants' contributions, especially in breakout room discussions were are summarised in the next section.

Key themes

Carer rights and recognition

Family and friend carers are crucial to supporting a significant part of the population to achieve positive health outcomes while reducing the strain on public health and service systems. However, participants reported continued limited recognition of carers' rights, the impact of caring on their health and life outcomes, and the value of their unpaid labour to the broader community. More research on the value and cost of caring was identified by participants as a possible solution to shift the understanding of caring from being a private obligation to a public responsibility.

Participating carers also expressed the need to advocate more strongly for themselves in the current policy landscape, but noted challenges such as limited funding, the level of input required, and their own caring responsibilities. Participants voiced the need to be equipped and supported to participate in advocacy, and to be remunerated and recognised for their valuable contributions. Greater representation in committees and the establishment of a Carers' Commission and/or a political group were suggested by participants to ensure carers' views are well-represented.

Definition and usage of the term "carer"

The term "carer" is often conflated or used interchangeably with other population groups such as paid care workers or parents with traditional caring responsibilities. Participants observed that this impacts carers' visibility and the recognition of their expertise, complex needs, and relational nature of their caring role, particularly within service systems they view to be increasingly consumer-driven. Suggestions from participants include consistent use of terminology across policies (e.g. Carer's Leave) and consideration of the inclusion of former carers in the definition of carers to acknowledge their unique needs after active caring has ended.

Flexible and accessible carer services

Carers are a diverse group with unique and individual needs. However, participants' experiences with a limited suite of services and strict parameters for accessing these resulted in many being unable to maximise the funding available to them for their wellbeing. Participants emphasised the need for respite services to be more responsive to the individual circumstances that shape carers' needs, and recommended funding to access

services be more flexible to accommodate these differences. Embedding more peer workers within service providers was also suggested to help promote flexibility in managing the services carers can access.

Further, participants agreed that services promoting carers' wellbeing should recognise that support for education, professional development, community engagement, or other personal goals enables carers to strengthen their identity and network outside of their caring role, which are integral to their wellbeing. Overall, it is important for carers to have greater flexibility and control over what type of services they can access and where, and how they use their funding in consideration of their diverse needs and the long-term impact of caring on their health and wellbeing.

Access to Carer Payment, Health Care Cards, and concessions

Carers often have reduced economic opportunities or lifetime earnings due to limited access to education and stable employment in the context of their ongoing or previous caring roles. Participants verbalised the need for policy to reflect an understanding of this and to alleviate some of the economic impacts of caring. Providing access to Health Care Cards and other services at concession rates was suggested by participants to help ensure carers have sustained financial capacity to support themselves and the persons receiving care. Additionally, participants emphasised that Carer Payments for former carers should realistically reflect the support they need as they transition out of their long-term caring role.

Employment rights and entitlements

There are existing rights and entitlements intended to support carers in the workplace but participants reported multiple barriers limiting access, including carers and/or their employers often being unaware or not having a comprehensive understanding of these entitlements. Participants also noted that supports can be dependent on employment status, restricting access for many carers who reduce hours or engage in casual work to balance their caring responsibilities. Further, participants felt that lack of recognition for carers may lead to stigma following disclosure.

Equipping employers and managers to understand and recognise who carers are, their rights and entitlements, and how to best support them in accessing these entitlements in their workplace was suggested by participants. They also emphasised how carers need to be supported to know and advocate for their rights where they exist.