Empowering carers when systems are complex

Policy paper - Carer Knowledge Exchange Interactive webinar 8

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 eight interactive webinars.

About Interactive webinar 8

Interactive webinar 8 was the third in a series of CKE webinars focusing on the priority area two of the NSW Carers Strategy 2020-2030: *carer recognition, respect and empowerment*. Building on carer, researcher and health practitioner perspectives on the topic shared in a prior webinar, Interactive webinar 8 was aimed at a policy audience and focused on the topic: 'Empowering carers when systems are complex'.

In addition to presenting panellists, a total of 81 attendees joined the session, 39% of whom identified as carers, with others bringing carer-focused research, policy and practice perspectives.

A facilitated panel discussion featuring three researchers and three carers (pictured above) drew on their personal and professional experiences to propose how carer empowerment can be promoted and sustained in service settings.

The panel was followed by six workshop-style breakout room discussions which aimed to draw on the expertise of attendees to identify opportunities for service systems to identify opportunities within the current policy environment to move towards more integrated service settings that better streamlines access to information and support for carers.

The full recording of Interactive webinar 8 is available on the CKE digital platform and the Carers NSW YouTube channel.

About this policy paper

This policy paper outlines the key themes that emerged from the facilitated panel discussion in the first half of Interactive webinar 8, featuring carer and researcher perspectives on the topic, and from the subsequent breakout room discussions with attendees.

This policy paper aims to apply these findings and recommendations to the significant opportunity presented by the development of a National Carer Strategy in the second half of 2024 to improve integration of services and coordination of policies across governments, as well as improve carers' experiences across these different service systems, identified priorities in the Department of Social Services discussion paper.

The themes and recommendations below are based on analysis of the event recording and of notes from breakout rooms, conducted by the Carers NSW Policy team.

Key themes

The following themes emerged from panel contributors and breakout room discussions:

1. The extent and impact of the administrative load on carers

Participants highlighted the extensive administrative components of caring, such as completing forms, coordinating and chasing up services, and finding information. These aspects of caring – distinct from meeting the day to day direct support needs of the person receiving care – were perceived as particularly exhausting and frustrating. The level of busyness, stress and confusion resulting from the administrative load was seen to be associated with chronic burnout.

2. Assistance with service access and coordination

It was noted that if service systems were not so complex, support and training with service navigation would not be required. While some carers are confident in self-advocating for support and finding the information they need to navigate service systems, other carers simply do not have the time, energy, resources or language capability to do so and either need a key worker to assist them, or the services themselves to become less complex. It was also acknowledged that carers' capability to navigate service systems may change over time, and they should always have the choice to manage themselves or access support.

3. Integrated vs. siloed service systems

Greater connectedness between the discrete service systems that carers often access concurrently (e.g. aged care, disability, income support, carer support, health care and social housing services) was identified as a key solution to reducing system complexity for carers. A single point of contact, pathways for warm referral between systems, and sharing of personal data across systems (with consent) were all identified as strategies to support this integration. Improved communication and collaboration between service systems and government departments was also a noted priority.

4. Carer-aware service systems

In order for services to be responsive to carers' needs, the service systems that carers access need to better understand who carers are and why they are important. Improving carer recognition and inclusion across government policy and service systems through a whole-of-government approach will assist carers to be more visible and supported.

5. Supporting informal initiatives in the community

The benefits of peer support and informal networks for sharing information and strategies, channelling frustrations into joint advocacy, and processing disappointments was a common theme. Supporting and resourcing active peer networks accessible to carers from all backgrounds and locations was identified as a key priority for governments.

Recommendations

In the light of the feedback shared by participants, Carers NSW proposes the following:

Recommendation 1: Include improved service navigation as a priority in the National Carer Strategy.

Recommendation 2: Explore the development of key workers who can assist carers to navigate service access and provide support with the administrative load of caring.

Recommendation 3: Increase communication and data sharing between the major service systems accessed by carers, e.g. the NDIS, My Aged Care and Carer Gateway.

Recommendation 4: Ensure that government grant opportunities focused on building community networks and social relationships include carers as a priority population to enable the establishment of new or innovative peer support approaches.

Recommendation 5: Recognise and monitor the administrative load of caring as distinct from the direct provision of care.

Recommendation 6: Invest in community-wide awareness raising about carers and strengthen requirements of government service providers to understand and recognise carers.