

Carers Victoria Submission to Legislative Council Environment and Planning Committee Inquiry into Community Consultation Practices

June 2025

Setting the scene

Community consultation practices are fundamental to the operation of contemporary governments with the community expecting more opportunities for meaningful feedback and demonstration that the feedback is valuable and has been listened to. Opportunities to have a 'seat at the table' alongside technical experts, policy makers and elected officials are particularly important for disadvantaged or vulnerable groups in the community.

Carers Victoria welcomes regular review and refinement of approaches and practices to ensure Victorian government consultation processes are aligned with community expectations and lead the way with best practice.

We appreciate the Committee's interest in a wide-ranging review of community consultation practices as expressed in the Terms of Reference and welcome the Committee's willingness to accept our submission which relates to consultation practices more generally and not only those related to planning and the environment.

For unpaid carers, a seat at the table is essential as the unique nature of their role gives them invaluable insight into policy development and service delivery. Their input can also ensure policies better respond to the needs of carers as unique service users.

We find that carers are not consistently included during policy and service development and their experiences, views and insights are often not valued to the same extent as consumers and clients of services. Carers Victoria recognises that the perspectives of both carers and the people they care for are essential to help ensure well designed, responsive and inclusive policies, practices and services. In this submission, we propose several ways that consultation processes can be enhanced to improve engagement with carers.

About Carers Victoria

Carers Victoria is the peak body for unpaid carers in Victoria. We are committed to changing the lives of carers for the better and ensuring that they have a voice that is heard, included and respected. A critical part of all our projects, services and advocacy is to work across all parts of our community to ensure all unpaid carers are recognised, valued and supported. Carers Victoria provides a range of assistance to carers including opportunities for connection through events, education, and networks; provision of information and advice curated to meet the needs and interests of carers; access to funded respite; and other opportunities to improve social connectedness. It also gives carers an opportunity to have their voice heard through policy and advocacy activities that are informed by what carers tell us matter to them, with Carers Victoria both developing its own Victorian-specific submissions and contributing to national submissions via the National Carer Network.

Further information about our organisation is at the following link Home | Carers Victoria.



Victorian Carers - Key Data¹

- There are over three quarters of a million carers in Victoria
- 54% of all Victorian carers are women and 46% are men a slight increase in the number of men undertaking care roles from 2018
- Carers are all ages but are most likely to be aged 45-64 (34%), with 13% of carers under the age of 24; 28% aged between 25 and 44 years; and 25% are aged over 65 years
- Around 15% of carers provide care to more than one person, and time spent providing care can be well above the requirements of a full-time job.
- 39% report living with a disability themselves.
- At least 21% of Victorian carers are born in a non-Main English-Speaking Country

Primary carers

There are close to 300,000 primary carers in Victoria (over one third of the Victoria's carer population); a person who provides the most assistance with core activities (mobility, self-care and communication). This is a 30% increase from 2018.

- Women were more than twice as likely to be primary carers (70% being women)
- 85% were sole primary carer
- 45% were living with a disability (compared with 37% in 2018)
- 32% spend 40+ hours caring, up from 22% in 2018.

Improving carers' inclusion and participation in community consultation practices

Carers Victoria welcomes the opportunity to provide this submission to the Environment and Planning Committee Inquiry into Community Consultation Practices.

Our submission relates to consultation practices more generally and not just those related to planning and the environment and makes the case to identify carers as a priority group in community consultations. We have identified a range of areas where we believe

¹ Australian Bureau of Statistics, Survey of Disability, Ageing and Carers, 2022; TableBuilder



community consultation practices could be enhanced. In summary, we recommend that community consultation practices:

- 1. utilise the definition of carers in the *Victorian Carer Recognition Act 2012* to support clarity (in terms of who carers are) and consistency across programs and services;
- 2. identify carers as a priority group for consultation due to their vital role and to mitigate the impact of service, policy and funding changes on this cohort;
- 3. recognise the diversity of carers and design consultations accordingly;
- 4. include carers in shaping the design and implementation of consultation practices to ensure they are accessible, and respectful of carers' time and energy; and
- 5. reimburse carers for any out-of-pocket costs and provide meaningful compensation for their time and expertise.

Utilise the definition of carers in the Victorian Carer Recognition Act 2012 to support clarity and consistency

The definition of carer under the *Victorian Carer Recognition Act 2012* is anyone who provides care to another person in a 'care relationship', including carers aged under 18 years, who has a disability, mental illness, is an older person with care needs, or has an ongoing medical condition. This definition is similar to that used in the *Australian Carer Recognition Act 2010* and should be used to support clarity (in terms of who carers are) and consistency across programs and services.

Identify carers as a priority group for consultation due to their vital role and to mitigate the impact of service changes on this vulnerable cohort

The role carers play is essential to the health, wellbeing and livelihood of the person (or people) they care for, whether a child, partner, parent, sibling, other family member or friend. Their range of responsibilities often include personal care, healthcare, transport, advocacy, communication, cognitive and/or emotional support, household tasks and behaviour support. Approximately 30% of carers provide care to more than one person, and time spent providing care can be well over and above the requirements of a full-time job.²

Carers' crucial role in our community is also reflected in the estimated economic value of their roles - more than \$77.9 billion in equivalent hours of paid support to the national economy, preventing unsustainable demand for services and underpinning the ongoing viability of Victoria's health and social support systems³.

The personal impacts of care roles can be significant:

• Carers' health and wellbeing is consistently much lower than those who do not have care roles.

² Carers NSW, 2024: 2024 National Carer Survey. Summary tables for Victoria.

³ 'Caring Costs Us: The economic impact on lifetime income and retirement savings of informal carers- a report for Carers Australia', 2022 carersaustralia.com.au/programs/caring-costs-us/



- Carers are experiencing high levels of financial stress and are unlikely to have financial reserves to endure unexpected shocks or expenses or long-term financial security compared to those who do not have care roles.
- Carers experience significant social isolation at twice the rate of those who are not in care roles.⁴
- An increasing number of carers are working less than they wish and over two thirds of Victorian carers report their caring duties prevent them doing as much paid work as they would like.⁵

Despite their huge contribution to society, and legislative recognition at state level since 2012, less than 12% of Victoria's carers felt that their caring role was recognised or valued by government in 2024 (a decline from an already low base of 16% in 2022)⁶.

Through Carers Victoria's recent consultations with carers, carers told us that they often feel isolated when confronting the significant challenges that are part of their day to day lives, that they are invisible and that their needs are not adequately considered by governments and service providers. Carers said that these consultations provided them with an important sense of community and validation by hearing others' stories and realising they are not alone in their struggles. Carers also valued the opportunity to express their concerns, believing their experiences and suggestions would lead to better outcomes for carers.

As a peak body advocating for unpaid carers to government and other stakeholders, we often find that the commitment to 'consumer' or 'person-centred' care or services can relegate carers to the margins rather than as critical stakeholders. This is evident in the lack of consistent or meaningful opportunities to contribute to service system reforms in health and community services leaving many carers who support people accessing those systems feeling actively excluded and unheard.

It is critical that carers are regularly consulted on policy, programs and funding decisions that may impact their caring role. This applies to social services but also includes disruption to essential services, transport, and local community infrastructure where change could have a disproportionate impact on their lives and those of the people they care for.

Consultation processes should reflect the fact that carers are unique service users and include them as such, considered as individuals with deep expertise in systems and services for their own needs, for the people they care for, and care relationships.

A positive example has been occurring in mental health policy and service delivery since the Mental Health Royal Commission recommended that there be specific consultation and engagement processes with the family, carers, kin and supporters of consumers separate to those with consumers themselves, as well as opportunities for joint consultation to occur.

⁴ Mylek, M. and Schirmer, J. 2024. Caring for others and yourself: Carer Wellbeing Survey 2024 report.

⁵ 2024 Carer Wellbeing Survey data tables, version 1.0, October 2024, University of Canberra.

⁶ Carers NSW, 2024: 2024 National Carer Survey. Summary tables for Victoria.



Such an approach reflects our view that the most successful advisory functions are those where a diversity of opinions are invited and shared.

Recognise the diversity of carers and design consultations accordingly

Carers are not a homogenous group, their care roles are unique, and their experiences reflect their diversity and intersecting identities. Carers are also under stress. It can be difficult to engage with carers due to the demands of their role.

Carers Victoria believes it is important that consultation practices respond to people's circumstances and demonstrate understanding of both the diversity of carer experience and the complexity of many care roles. This will help to engage carers who are currently underrepresented in consultations including those not accessing formal supports. The involvement of people with lived or living experience of caring as facilitators of consultation processes is also invaluable to ensure participants are well supported and understood in these processes. All the above are important considerations in the design of meaningful consultation practices.

Reliance on the Engage platform which usually allows for a written submission to be uploaded, or a survey completed, will invariably exclude some members of the community, including carers who may not have high digital literacy or access to reliable internet. Language may be a barrier for carers from culturally and linguistically diverse backgrounds, particularly those from emerging communities where communication is predominantly oral. We suggest that alternative methods of communication such as voice or video files and public forums are offered to provide carers wider options for participation.

A flexible, mixed methods approach combining surveys, a submissions process (with both written and audio options), online and in person forums, and in-depth qualitative interviews or focus groups is a valid approach for consulting hard to reach groups.

As a government funded peak body, Carers Victoria operates as both a provider of support to carers and an advocate for unpaid carers across the state. With over 30 years' experience, each year we engage with thousands of Victorian carers through a wide range of interactions including service delivery, advice and information, events, surveys and focus groups. We regularly share the data and carer insights we gather with government departments and other organisations to help shape efforts to enhance the overall understanding of, and access to assistance for, unpaid carers. We also provide advice and guidance on how to effectively engage with carers to gather their insights and advice, and welcome requests to support government departments and other organisations with advice to guide their own targeted and public consultation processes with carers.

We believe utilising the expertise and networks of non-government providers and people with lived and living experience allows for a diverse mix of carers to be engaged, in ways tailored to their needs and preferences and that regular, ongoing engagement enables more meaningful dialogue between carers and policy makers.

Governments and the broader service sector need to similarly leverage their existing infrastructure of sector and community networks to distribute information and create ongoing engagement opportunities with carers. This kind of regular engagement helps to create alliances between policy makers, advocates and service systems, and identifies



partnership opportunities such as joint events, webinars or public forums that can be used to help address challenges as well as model best practice when consulting with carers.

Include carers in shaping design and implementation to ensure consultation practices are accessible, and respectful of carers' time and energy

It is critical that carers are actively involved in industry and government advisory structures to help shape policy and services. Carers' expertise can help relevant government departments and services target their programs more effectively, ensuring that services achieve the goals they are designed to reach.

Where possible, these advisory arrangements should be formalised, and carers appropriately resourced to participate. This is an important point, as carers may need to be supported to participate in consultation activities (both support for themselves, and/or the person they care for), and to have the resources and training necessary to effectively participate in discussions about policy and decisions that impact them.

Formal models such as a standing carer advisory committee (as is in place, or in the process of being established, in other jurisdictions) and/or inclusion of carer representatives on existing and new government advisory panels and committees are an important mechanism to ensure carers are involved in decisions about services that affect them. Elevating carer voice to help guide implementation and evaluation of new policies and investment decisions is vital and should reflect the diversity of Victoria's population and care roles.

Reimburse carers for any out-of-pocket costs and provide meaningful compensation for their time and expertise.

Carers participating in consultation activities are providing valuable insights and expertise based on their lived experience and should be compensated for their time and skills. In addition, participants should be reimbursed for any costs they incur. Those recruiting carers for consultation activities should help those receiving income support payments to understand the reporting obligations or tax implications of the reimbursements they are offering.

Some recent advice that provides a possible benchmark for organisations considering how to compensate and reimburse consultation participants are:

YACVIC guidance: <u>Youth Affairs Council Victoria</u> | <u>Paying young people</u> (includes useful guidance on tax treatment)

Justice Connect guide - Guide to consumer representative payments

Justice Connect guide - Payment of Board Members

DFFH - Recognising the expertise of people with lived experience: <u>guidance on payment</u>, <u>reimbursement and recognition</u>

In conclusion, thank you for the opportunity to provide this submission to inform this important Inquiry. Carers Victoria would be pleased to provide further advice to the Committee regarding strategies to ensure effective consultation with Victorian carers to inform future Victorian Government consultation processes.