Council on the Ageing
Queensland

Response to the review of the *Carers (Recognition) Act 2008* (Qld)

June 2026

Council on the Ageing
Queensland

Council on the Ageing Queensland is a for-purpose statewide charitable organisation.

We are the state's Seniors Peak and Seniors Social Isolation Prevention Peak and work with and for older adults, advancing the rights, needs, interests, and futures of people as we age. For more than 60 years, we have worked to influence positive social outcomes for older Queenslanders.

We connect directly with older Queenslanders, their families, carers, and organisations, service providers, consumer advocates, special interest groups, and our federal, state and local governments. We engage with all of these groups to understand needs, aspirations, and priorities for older people in Queensland, and partner to achieve the best outcomes for people as we age.

Our work includes policy analysis, community education, representation, evaluation and research, community engagement, and cross sector collaborations to achieve systemic change. We deliver funded programs directly to older people in need and provide sector support to those organisations who offer aged care and other services to older people.

We seek to eliminate ageism and support healthy ageing and growth of age-friendly communities. There are many areas of policy development needed to achieve this – elder abuse, energy, social isolation and loneliness prevention, climate resilience and disaster preparedness, digital inclusion, health, housing, and transport are just a few.

Our vision is that ageing is a time of possibility, opportunity, and influence.

With sincere thanks to the people who informed this response with their lived experience and expertise as carers and advocates.

Note on use of AI
A generative artificial intelligence tool was used to assist with organising themes from collated data and insights. Data analysis, interpretation, recommendations and conclusions were undertaken and reviewed by and remain the responsibility of COTA Queensland. See 'References' for details of sources consulted.

Council on the Ageing Queensland
Level 6, 10 Market Street Brisbane, QLD 4000
www.cotaqld.org.au
policy@cotaqld.org.au
(07) 3316 2999

Authorised by: Darren Young, Chief Executive Officer
Contact: policy@cotaqld.org.au

Acknowledgement
Council on the Ageing Queensland acknowledges Australia's First Nations Peoples as the original custodians of this land.

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Executive Summary

Council on the Ageing Queensland (COTA Queensland) welcomes the review of the *Carers (Recognition) Act 2008* (Qld) and the Queensland Carers Charter. As the peak body for older Queenslanders, COTA Queensland supports reform that strengthens recognition of carers not only for their contribution to Queensland's care systems but as individuals with their own rights, aspirations, economic security, and needs for their wellbeing, participation, inclusion and support.

Carers are essential to Queensland's health, aged care, disability, mental health, child safety, housing and community service systems. They provide unpaid assistance with daily living, personal care, transport, management of medication, service coordination, emotional support, advocacy, decision-making and crisis management. Yet too often, carers are expected to absorb the pressures and failures of fragmented systems without clear recognition, information, authority, respite or practical supports. COTA Queensland considers that the current Act and Charter have provided a critical foundation for formal recognition of carers, but reform is required to shift system behaviour, improve accountability by agencies and recognise the everyday experiences of diverse carers.

COTA Queensland supports a shift from symbolic recognition to practical recognition of carers and puts forward the following recommendations that the Act and Charter be strengthened through seven overarching recommendations:

Recommendation 1: Establish a rights-based framework for carer recognition

The Queensland Government should uplift the *Carers (Recognition) Act 2008* (Qld) and redevelop the Queensland Carers Charter through a rights-based framework. This should recognise carers and the people they care for as individuals with rights, dignity, preferences and changing needs, while also acknowledging carers' wellbeing, support needs, participation, inclusion and economic security. Recognition should extend beyond carers' social and economic contributions to include the impacts of caring on mental health, physical health, respite, workforce participation, income, superannuation and later life.

Recommendation 2: Improve recognition of diverse carers and care relationships

The Act should better reflect the diversity of care relationships across Queensland, including informal carers, older carers, grandparent and kinship carers, parents caring for adult children with disability, Aboriginal and Torres Strait Islander carers, culturally diverse carers, LGBTIQA+ carers, rural and remote carers, and carers living with disability, chronic illness or changing capacities. This should include updating the definition of carer and adopting a broader care relationship model that recognises informal, kinship and culturally diverse family structures. The Queensland Government should also improve culturally safe, trauma-informed and regionally accessible engagement, outreach and recognition, including for people who may not self-identify as carers.

Recommendation 3: Strengthen obligations on public authorities and relevant service systems

The Queensland Government should strengthen accountability by requiring public authorities and relevant services to identify, recognise, consult and include carers in decisions, policies, programs and services that affect them. Carers should be provided with clear information at key transition points, including diagnosis, intake, assessment, hospital discharge, aged care entry, service review and crisis points. Authorities should also document carer consultation, provide staff training on relevant legal, human rights and decision-making obligations, and establish clear escalation pathways where carers are excluded, ignored or not appropriately consulted.

Recommendation 4: Improve service navigation and recognition of legal and practical care roles

The Queensland Government should improve carers' interactions with service systems by clarifying the relationship between legal decision-making authority and practical everyday caregiving roles. This should include clear procedures for recognising legal authority, reducing administrative duplication, and preventing carers from having to repeatedly provide the same documents within the same organisation or system. Carer information and navigation pathways should also be widely promoted so carers can better understand their rights, roles, available supports and complaint options.

Recommendation 5: Strengthen monitoring, reporting and accountability

The Queensland Government should introduce stronger accountability mechanisms by reintroducing monitoring and reporting requirements for public authorities, particularly agencies and services that directly affect carers and care recipients. Public reporting should show how the Act and Charter are being implemented in practice, including how carer voices have influenced policy and service delivery. Independent oversight and evaluation mechanisms should also be established to assess implementation, outcomes and ongoing areas for improvement.

Recommendation 6: Strengthen the Queensland Carers Advisory Council

The Queensland Government should strengthen the role, visibility and effectiveness of the Queensland Carers Advisory Council. QCAC should be enabled to request information, monitor implementation, provide public updates, identify systemic issues and advise government on compliance and reform. Its visibility, accessibility and lived experience diversity should be strengthened through public communication, regional and online engagement, clear pathways for carers to raise issues, appropriate remuneration and support for lived experience members, and continued representation for grandparent carers.

Recommendation 7: Embed continuous review and improvement

The Queensland Government should ensure the Act remains contemporary, adaptable and effective by embedding a mandatory independent review at least every five years. Each review should assess implementation, accountability mechanisms, lived experience participation, diversity and inclusion, and outcomes for carers. Future reviews should include accessible consultation with carers across Queensland, including carers from diverse backgrounds, communities and care relationships.

This review is an opportunity to improve carer recognition in Queensland. Carers must be recognised as essential to Queensland's health, disability, and aged care systems, while also being supported as individuals with rights, needs and lives beyond their carer roles.

Opportunity to move beyond symbolic recognition of carers

Council on the Ageing Queensland supports reform of the Carers (Recognition) Act 2008 (Qld) to move from symbolic recognition toward a rights-based accountable framework that acknowledges carers as partners in care and as individuals with rights and needs for their own wellbeing and supports.

Council on the Ageing Queensland (COTA Queensland) is the peak body for older Queenslanders. COTA Queensland advances the rights, interests, needs and futures of older people and works to ensure that older Queenslanders age well, participate fully, and are recognised as valued members of their communities.

COTA Queensland welcomes the opportunity to provide feedback to the review of the *Carers (Recognition) Act 2008* (Qld) (the Act) and the Queensland Carers Charter (the Charter). This submission is informed by a rights-based approach to ageing and caring.

Carers are one of the most diverse population groups in Queensland. Older carers are spouses and partners, adult children, grandparents, grandparent carers, kinship carers, parents of adult children living with disability, neighbours, friends and people providing care through informal, culturally defined or family-based arrangements. Many older carers provide care while also living with their own age-related changes, disability, chronic health conditions, bereavement, trauma, financial insecurity, housing insecurity and/or social isolation.

Context of care and carers' lives

In the last two years, there has been a shift in thinking about carers' roles, their rights and their circumstances in which they are supported or not supported. For example, looking to public opinion and lived experience represented in the media shows that it is time to move beyond symbolic recognition and create stronger obligations across government, service systems and workplaces to identify carers, include them in decisions, protect their wellbeing, and recognise the economic value of unpaid care.

Further, it is clear that more representation of diverse care relationships is required including spouses and partners, adult children, parents of adult children living with disability, grandparents, grandparent carers and kinship carers, younger carers, older carers, culturally and linguistically diverse carers, and carers supporting people at home living with disability, chronic health and/or mental health conditions, dementia or frailty.

We highlight below key themes that have come from media in the last two years.

Media

Carers provide essential unpaid care across Australia, yet they remain poorly recognised in law, services and everyday systems. Unpaid carers include people supporting someone with disability, chronic health conditions, mental health, frailty due to age, or other care needs. Recent national developments including the 2024 - 2034 National Carer Strategy and recommendations from the Parliamentary Inquiry, indicate a growing need to modernise carer recognition, including by moving toward a broader understanding of the 'care relationship'. This shift is important because caring roles are diverse, often informal, and frequently invisible within systems that rely heavily on carers but do not always identify, include or support them.

The impacts of caring are significant and extend across carers' mental health, social connection, financial security, employment and wellbeing. Recent reporting on the 2024 National Carer Survey highlighted high levels of social isolation and psychological distress among carers alongside broader concerns about declining wellbeing. Many carers give up paid work, reduce hours or lose years of earnings and superannuation in order to care for family members, creating long-term impacts to financial health and retirement. Working carers can also face limited workplace flexibility, complex leave arrangements and income support rules that do not adequately reflect the realities of combining work, study, volunteering and care. At the same time, respite and practical supports remain insufficient, with media coverage describing carers as being at breaking point and carer support services experiencing unprecedented demand.

These pressures are experienced differently across diverse care relationships. Grandparent and kinship carers face distinct gaps in recognition of role and contributions particularly when raising grandchildren due to abuse, neglect, homelessness, illness, family crisis or cost-of-living pressures, with additional barriers for migrant and refugee grandparents. Older carers and 'sandwich generation' carers are also under-recognised including people simultaneously caring for dependent children and older parents, or older spouses or partners, and adult children supporting family members with changing capacities or chronic health conditions. Parents caring for adult children living with disability face lifelong planning concerns, including future care, legal and financial security. These challenges are further intensified when aged care, home care, disability and mental health systems are delayed, fragmented or unclear, leaving families to carry additional responsibility and navigate complex systems without adequate support.[1]

Research literature

Delving into the very recent research and academic literature, what becomes apparent is where caregiving is increasingly being understood as a social role with consequences for the carer's own rights, wellbeing, participation and inclusion. Historically, research has focussed on the needs of care recipients and viewed carers primarily as a resource that has driven the care economy - helping health, aged care and disability systems. The emerging literature recognises carers as individuals whose lives, finances, employment, relationships, health, housing, retirement security and community participation are profoundly shaped by caregiving responsibilities.

Key themes that have appeared in the research literature are provided in Table 1.[2]

[1] Media sources are listed under References. All media sources with the exception of the SBS 2014 article have been included as recent evidence. These are example sources and not an exhaustive list. Earlier media is treated as historical context.

[2] Research literature is listed under References. The reference list includes studies from 2025 – 2026 which have been referenced in Table 1. in addition to key earlier works or studies regarding e.g., grandparents, older carers, carers, and caregiving within families.

Table 1. Recent studies and the shift to a focus on carer wellbeing and rights and relevance to Queensland context of care

Theme	Evidence	Relevance to QLD context of care
Recognition of carers as partners in care	Mental health and co-production research increasingly views carers as experts and partners rather than passive supports.	Recognition should extend beyond acknowledgement to meaningful participation in care planning, policy design and service delivery.
Work/care conflict	Emerging work/care literature shows carers simultaneously occupy roles as worker, spouse, parent, adult child and community member. Caring responsibilities frequently constrain employment opportunities.	Supports stronger recognition of workplace participation rights and flexible employment arrangements.
Financial insecurity and economic penalties	Research demonstrates that carers often remain financially insecure even when earnings increase. Crossing income thresholds can worsen arrears, financial stress, dissatisfaction with income and inability to save due to policy design features. Economic insecurity is particularly pronounced among lower-middle incomes working carers and rental tenants.	Recognition must include economic participation, income security, superannuation impacts and avoidance of policy settings that inadvertently penalise carers.
The hidden costs of caring	Research identifies out-of-pocket expenses, foregone employment, reduced retirement savings, transport costs, health costs and reduced economic opportunities. Examples highlight financial deterioration among some carers during COVID despite government supports.	Supports recognition of caregiving as an activity with significant economic consequences requiring policy consideration.
Older carers and spousal carers	Research highlights fatigue, role strain, isolation and continuous responsibility among older spousal carers, particularly women. Caring often becomes a 24-hour role.	Older carers should be recognised as a priority group with distinct needs related to ageing, health and retirement security.
Mental health, stress and burnout	Across studies, carers experience anxiety, distress, emotional exhaustion and psychological burden. Research found increased anxiety, frustration, stress, social isolation and emotional strain during caregiving.	Recognition should explicitly include carer wellbeing, not solely care recipient outcomes.
Social isolation and loneliness	Many carers report reduced social participation, loss of community connection and limited opportunities for social engagement. Pandemic conditions intensified these issues.	Supports obligations to consider carers' social inclusion and community participation.
Navigation of complex systems	Dementia, aged care and disability studies repeatedly identify fragmented systems, poor coordination and administrative burden. Research	Recognition should include system-wide responsibility to identify and support carers rather than expecting carers to self-navigate.

Theme	Evidence	Relevance to QLD context of care
	highlights 'red tape,' fragmented services and difficulties accessing support.	
Respite and practical support	Carers consistently identify respite as one of the most important forms of support. Lack of respite contributes directly to burnout and role overload.	Strong rationale for recognising access to respite as a core support need.
Information and communication	Many carers report not knowing what supports exist, difficulty accessing information, and poor communication from systems and services.	Recognition should include a right to information and clear communication.
Emotional support and connection	Carers repeatedly report needing someone to talk to, regular check-ins, and recognition of their emotional burden.	Supports a broader understanding of support that includes psychosocial wellbeing.
Hospital-to-home transitions	Studies indicate that structured support following discharge improves confidence and reduces caregiver burden.	Highlights the need for carers to be formally recognised at transition points.
Culturally diverse carers	Example from New Zealand demonstrates Māori caregiving emphasises whānau, reciprocity, collective responsibility, social capital and cultural identity. It highlights disruption of cultural practices and the need for culturally responsive services.	Supports recognition of diverse care relationships and culturally informed support models.
Rural carers	Rural carers experience service shortages, workforce shortages, distance barriers and reduced access to support.	Supports place-based approaches to recognition and support.
Grandparent and kinship carers	Research increasingly recognises grandparents and kinship carers as significant contributors to family care systems, often balancing employment, retirement and childcare responsibilities.	Supports broader definitions of care relationships beyond traditional models.
Carers during emergencies and disasters	Research shows carers are critical but vulnerable during emergencies, experiencing service disruption, isolation, increased care demands and financial strain.	Recognition frameworks should explicitly consider carers in emergency planning and disaster response.
Future planning and lifelong caring roles	Parents caring for adult children living with disability face lifelong caring responsibilities and concerns about future care arrangements.	Recognition should reflect the longitudinal nature of caregiving.

Undertaking a thematic analysis of the collective research above from public opinions and voices including lived experiences from the media and the original research studies, there are five major themes which become evident in care contexts and carers' lives (particularly since COVID). These include:

1. Recognition is moving beyond symbolism

Recognition should not simply mean acknowledging carers' contribution. Recognition must be reflected in how agencies behave and whether carers are identified, listened to, included in decision-making and supported through services and policy systems.

2. Carers experience their own forms of disadvantage

Financial insecurity, employment penalties, reduced retirement savings, social isolation, psychological distress and poorer health outcomes among carers. These impacts often persist even where formal supports exist. Policy settings can sometimes create or worsen insecurity rather than reduce it.

3. Care is relational and diverse

There have been more research and published work that challenges narrow assumptions about who carers are and what caring looks like. Care relationships include spouses, partners, adult children, parents of adult children living with disability, grandparents, grandparent carers, siblings, neighbours, friends, kinship carers and culturally defined family relationships. The research suggests that policy frameworks need to recognise this diversity rather than relying on a narrow model of dependency and care.

4. Carers are essential infrastructure

Across aged care, disability, mental health, chronic illness, dementia and palliative care research, unpaid carers are increasingly described as indispensable to the functioning of care systems. Without them, formal systems would struggle to meet demand. Yet carers frequently report fragmented services, administrative burden and inadequate support.

5. One-size-fits-all approaches do not work

Recent studies emphasise that carers are not a homogeneous group. Experiences differ according to age, gender, income, employment status, cultural background, geographic location, relationship to the care recipient and the nature of the caring role. No single model of support is appropriate and advocates flexible, context-specific and culturally responsive approaches.

Therefore, the evidence suggests that contemporary policies and directions should move from a framework of recognition of contribution to a framework of **recognition of rights, participation, wellbeing and inclusion**. Carers are increasingly understood as providers of care *and* as individuals whose social, economic, cultural and health needs require consideration across government, workplaces, health, aged care, and disability service systems, and community life.

Voices of lived experience

COTA Queensland, through its engagement in person, via email, online survey insights, and over the phone, has connected with older Queenslanders, carers, lived experience representatives, advocates and communities who have provided their stories, ideas, and thoughts regarding their lived experiences of care contexts and carer roles.[3]

It is through these collective voices and insights that COTA Queensland highlights below nine areas for consideration in relation to the review of the Act and the Charter in addition to recommendations.

1. A rights-based approach to recognition

Carer recognition must move beyond a focus on carers' contributions and toward recognition of carers' rights, wellbeing, participation and inclusion.

Carers provide essential unpaid support across Queensland. They assist people with daily tasks, personal care, healthcare coordination, transport, finances, emotional support, social connection, communication with services, medication management, advocacy and decision-making. Many also coordinate multiple systems at once, including hospitals, general practice, aged care, disability services, agencies under Services Australia, child safety, mental health services, housing services, the Office of the Public Guardian, the Public Trustee and community organisations.

In practice, carers often act as the primary coordinators of care, but without formal recognition, authority, training, respite, information or support. As one carer with lived experience stated:

> *Carers often act as the primary coordinators of care, yet they do so without formal support or recognition. The government should acknowledge that carers are essential to the functioning of the health, disability, and aged care systems. This requires more than symbolic recognition. It requires clear rights, consistent operational behaviour, and mechanisms that ensure agencies meet their obligations.*

COTA Queensland supports a shift from symbolic recognition to practical recognition. This means carers should be identified, listened to, included in decisions, supported in their role, respected for their knowledge, protected from avoidable administrative burden and recognised as individuals with their own health, wellbeing, social, economic and participation and inclusion.

Carers are not a health resource for aged care, disability, mental health and community systems - they are individuals whose own lives, finances, employment, housing, retirement security, relationships, health and community participation can be profoundly affected by caregiving responsibilities.

[3] These insights include an interview with a carer and advocate, telephone conversations with carers and advocates, lived experience representatives, and survey data through the Ageing Well survey. View COTA Queensland references section.

2. Recognition of carers in the Act and the Charter

COTA Queensland views that the Act and the Charter do not currently provide sufficient recognition of the breadth, diversity and lived realities of carers in Queensland. The Charter contains important principles including recognition of carers' dedication, respect for carers, consultation with carers, consideration of complaints, recognition of carers' knowledge and experience, and specific acknowledgement of young carers, grandparent carers and rural and remote carers. However, COTA Queensland has heard from carers and advocates that the Charter is not sufficiently embedded in systems or carried out in practice. Further, the Charter is broad and aspirational and not reflective of diverse experiences of carers:

> *The current Charter contains broad aspirational statements but does not create clear obligations, measurable outcomes, or meaningful accountability mechanisms. How does the carers charter reflect the experiences of all carers? Again, where is the evidence to support consultation with representative bodies? How do government, policy makers and decision makers interact with the carer community to access feedback from lived experience? As stated in the Carer Charter Part 2, 8, (2) there are no legally enforceable obligations on anyone.*

Carers and/or advocates noted that young carers, grandparent carers, rural and remote carers, culturally diverse carers and Aboriginal and/or Torres Strait Islander carers each experience different structural barriers that are not adequately reflected in the current Charter:

> *The current Carers Charter is broad and aspirational, but it does not reflect the varied experiences of different groups. For example, young carers often manage schooling alongside significant responsibilities, yet the Charter does not address the need for flexible education arrangements. Grandparent carers frequently navigate both parenting and ageing-related challenges, but the Charter does not recognise this dual burden. Carers in rural and remote areas face limited service availability and long travel distances. The Charter does not acknowledge these structural barriers. Culturally diverse carers may require interpreters or culturally appropriate services, yet the Charter does not specify how agencies should respond. First Nations carers often operate within kinship structures that differ from mainstream service assumptions, but the Charter does not reflect this reality.*

Therefore, there is not sufficient recognition of the diversity of care relationships including informal care, kinship care, care provided by older spouses, care provided by parents of adult children living with disability, care provided by older people who are themselves living with changing capacities, and care provided through Aboriginal and/or Torres Strait Islander kinship structures or culturally diverse family systems.

The Queensland Carers Charter needs to be redeveloped through a rights-based approach. This should include recognition that:

- carers are people with their own rights, wellbeing, and support needs
- carers should be recognised as partners in care, planning and decision-making
- carers' knowledge, experience and relationship with the person they care for should be respected

- carers should be meaningfully consulted in the design, delivery and review of policies, programs and services that affect them
- carers should be able to access clear information, navigation support and escalation pathways
- carers should not be expected to absorb the failures of fragmented service systems, and
- carers from diverse backgrounds and circumstances may experience additional structural barriers and require tailored, culturally safe, trauma-informed and accessible recognition.

The Charter should also explicitly recognise older carers and carers who are themselves living with disability, chronic health conditions, changing capacity, housing insecurity, financial hardship, social isolation or trauma.

3. Diversity and invisibility in caring roles

A significant barrier to effective recognition is that many people undertake caring responsibilities that do not identify themselves as carers. Evidence suggests that this is common among diverse groups of carers such as older spouses, adult children caring for parents, grandparents raising grandchildren, culturally diverse carers, Aboriginal and/or Torres Strait Islander carers, parents caring for adult children living with disability, and people providing informal care to family members, friends or neighbours.

This lack of self-identification is not just terminology and language but also has practical consequences. People who do not identify as carers may be less likely to seek support, be recognised by services, included in decision-making, or participate in consultation processes. Public authorities and/or relevant service systems may also fail to recognise them unless the legislation, the Charter, policies and operational practices require a broader and more proactive approach:

> *I look after my* [...] *disabled daughter (CP) and my husband who has cancer.*
>
> *I am a full-time carer for* [my] *husband that has dementia and am 81 years old...it's hard!*
>
> *As a carer burn out happens.*

These experiences demonstrate that caring is often cumulative and intersects with ageing, disability, health conditions, gender, income, housing, geography and family responsibilities. Older carers may be managing their own health appointments, mobility changes, fatigue, bereavement, financial stress and social isolation while also providing care to another person.

Grandparents, Grandparent Carers and 'informal' carers

Grandparents, grandparent carers and 'informal' carers face unique systemic barriers.[4] They may be navigating child safety, schools, Services Australia agencies, housing, family violence, trauma, legal processes and their own ageing-related needs while providing primary care to grandchildren. COTA Queensland has heard that these types of carers frequently navigate both parenting and ageing-related challenges. However, the current Charter does not adequately recognise these dual responsibilities.

Informal carers also remain under-recognised. Some people provide substantial care without formal legal authority, without a formal service relationship (without formal recognition of a care dyad), or without recognising themselves as carers. This invisibility can mean they are excluded from planning, information and support, even when they are carrying the day-to-day responsibilities of part-time or full-time care.

Carers who are partners or spouses

Caring for a spouse or partner can transform a long-standing relationship into a care relationship and quickly become a full-time care role. This can be emotionally, physically and socially demanding, particularly where the carer is also ageing or living with their own health conditions. As one carer explained: "You don't get a book on how to do it." This reflects the reality that many older carers are left to self-educate, advocate and navigate systems, sometimes in crisis, rather than being proactively identified or self-identifying earlier and being supported sooner.

Intersectionality

The Act must explicitly reflect the diverse realities of carers, including Aboriginal and/or Torres Strait Islander carers operating within kinship structures; culturally diverse carers who may require interpreters and translators and culturally responsive information and culturally safe services; 'sandwich generation' carers supporting both children and older parents; rural and remote carers facing long travel distances, service shortages and limited local supports; LGBTIQA+ carers; carers impacted by trauma; carers experiencing housing stress or financial hardship; and carers who are themselves are living with disability, chronic health conditions or changing capacities.

A one-size-fits-all approach will not suffice. Future legislation should reflect the diversity, complexity and changing nature of care relationships.

4. Obligations and accountability for public authorities

COTA Queensland supports strengthening obligations on public authorities and improving accountability mechanisms under the Act. The current obligations on public authorities are not

[4] In this submission, COTA Queensland recognises that grandparents who provide informal care on an irregular, semi-regular or regular basis for e.g., grandchildren, are different to grandparent carers who step into a direct caregiver role (a parental role) with full-time care responsibilities. The descriptor of 'informal' is not to detract from the substantial commitment and responsibilities that both roles undertake; rather, we acknowledge that each role brings unique considerations for carer recognition, needs, and rights.

sufficient to ensure carers are consistently recognised, consulted, included or supported. Public authorities are expected to ensure employees understand and reflect the principles of the Charter, consider the Charter in relevant human resource policies, and consult with relevant carer representative bodies when making strategic policy or planning decisions affecting carers and those they care for. However, these obligations are not legally enforceable and failure to comply does not affect the validity of decisions.

This creates a gap between recognition in principle and recognition in practice. Carers have told COTA Queensland that services do not consistently understand or respect their role:

> *Carers need to be involved at the beginning not left to an afterthought*.
>
> *Engage with carers*. *At the moment we get a pat on the head* [and] *are told 'off you go' to your full time unpaid caring role*.

Carers do not consider the Act including the Charter as practical tools that shapes service behaviour; rather, recognition appears inconsistent, discretionary and dependent on the attitudes or knowledge of staff in individual encounters with e.g., service and support agencies.

COTA Queensland recommends that the Act be amended to clarify and strengthen authorities' obligations. These obligations should require public authorities to:

- identify carers at key points of contact, including assessment, intake, diagnosis, hospital admission, discharge planning, service review and care transition points
- provide carers with clear and accessible information about their role, rights, available supports and escalation pathways
- recognise carers as partners in care planning and service delivery, subject to the rights, preferences and consent of the person receiving care
- document how carers have been consulted in decisions that affect them or the person they care for
- ensure staff are trained in the Act, the Charter, human rights obligations, substitute decision-making law, privacy, consent and supportive decision-making
- ensure that legal decision-making authority, including Enduring Power of Attorney arrangements, is verified and respected where relevant
- reduce administrative duplication, including repeated requests for the same documents within the same organisation or system
- establish clear escalation pathways where carers are (or feel they are) excluded, ignored or not appropriately consulted
- consult with carers and carer representative bodies early in policy, program and service design rather than after key decisions have already been made, and
- report publicly on implementation of their obligations.

Strengthening obligations does not mean that carers' views override the rights or preferences of the person receiving care. Rather, it requires authorities and services to recognise that carers - who often hold critical information about the person's needs, routines, risks, preferences and circumstances - are deeply affected by decisions and decision-making processes.[5]

[5] We refer to obligations on public authorities and relevant service systems to the extent within Queensland's legislative, funding, commissioning, contracting and service delivery powers.

5. Legal authority, practical care and service navigation

COTA Queensland recommends that the Act and Charter provide clearer recognition of the relationship between legal authority, practical care and everyday caring roles. COTA Queensland has heard concerns about confusion or the lines being blurred between, for example, Enduring Power of Attorney arrangements and practical caregiving. In some cases, a person may hold legal authority but not provide daily care. In other cases, the person providing substantial daily care may not hold formal legal authority. In practice, carers may be excluded from conversations even when they hold formal authority or they may be expected to coordinate care without being given the information or recognition required to do so effectively.

> *Decision making - only if they are forced to.*
>
> *The legislation appears to be a series of motherhood statements. I would like to see some examples from government and others about what they are actually doing to support carers.* [This] *has been my experience over the last couple of years as a full-time carer for my husband who had motor neurone disease.*

Further examples include when carers have reported situations where an aged care provider may insist on speaking only to the resident even when the resident has impaired decision-making capacity and the carer holds formal authority under an Enduring Power of Attorney. This creates unnecessary stress, confusion and administrative burden.

COTA Queensland recommends that public authorities and relevant service systems be required to implement clear procedures for e.g., identifying and recording the person's nominated carer or support person; any person providing substantial informal care and/or holding legal decision-making authority; the person's consent and preferences about carer involvement; what information can be shared with the carer, and how the carer should be involved in planning, transitions, discharge and review processes.

Further, there needs to be wider promotion of primary contact points and navigation supports for carers seeking information about their rights, service pathways, complaints, legal authority and practical supports.[6] Carers should not be left to navigate complex systems alone particularly when they are time-poor, distressed or managing intensive caring responsibilities.

6. Monitoring, reporting and accountability

COTA Queensland strongly supports the inclusion of monitoring, reporting and accountability mechanisms in the Act. Without transparent reporting, it is difficult to assess whether e.g.,

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[6] Examples of existing supports for carers in relation to older cohorts:
Australian Government. (n.d.). *Carer Gateway* [Website]. https://www.carergateway.gov.au/
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public authorities and relevant service systems understand the Charter, staff are trained, carers are consulted, complaints are acted upon, or whether the Act is making a practical difference.

Further, previous reporting obligations were removed which subsequently has weakened transparency which may limit the ability of the Queensland Carers Advisory Council (QCAC) to e.g., promote compliance or advise the Minister on how public authorities are implementing the Charter. This review provides an opportunity for Queensland to align with best practice.

COTA Queensland recommends that reporting obligations be reintroduced. These should be proportionate and targeted with stronger obligations applying to agencies and services whose functions most directly affect carers and the people they support, for example:

- Queensland Health and Hospital and Health Services
- Queensland Government agencies responsible for older people, disability, child safety, mental health, communities and housing
- the Office of the Public Guardian and Public Trustee
- statutory bodies and public authorities providing services to carers or people receiving care
- publicly funded services that directly affect carers or care recipients
- agencies involved in disaster planning and emergency response, and
- agencies responsible for workforce, employment and human resource policies affecting employees who are carers.

Reporting should include practical indicators such as staff training, carer identification processes, consultation activities, complaints and escalation processes, actions taken to support diverse carer groups, and examples of how carer input has influenced policy or service delivery. COTA Queensland also supports independent review or oversight mechanisms to assess implementation. These mechanisms should be transparent, accessible and informed by lived experience.

7. Queensland Carers Advisory Council

COTA Queensland supports strengthening the role, visibility, authority and lived experience diversity of the Queensland Carers Advisory Council (QCAC). The current functions of QCAC include advancing carers' interests, promoting compliance with the Charter, making recommendations to the Minister on enhancing compliance, providing general advice, and carrying out other functions as directed by the Minister. These functions are important; however, without authorities' reporting or stronger mechanisms for QCAC to gather information, monitor implementation and communicate with carers, QCAC may be limited in its ability to fulfil these functions effectively.

In addition, many carers are unaware of QCAC and its role:

> *No, unless it is represented by bodies that I am unfamiliar with. As a former carer and registered nurse, I have not been aware of the QCAC existence.*

If carers are unaware of the Council, it cannot effectively represent their interests.

The Act needs to be uplifted to strengthen QCAC's role and visibility. QCAC should be empowered to:

- request information from public authorities about implementation of the Act and the Charter
- receive and consider public authorities' reports on implementation
- provide annual public advice or reporting on carer recognition in Queensland
- identify systemic issues affecting carers
- make recommendations to the Minister on legislative, policy and service improvements
- engage directly with carers across Queensland, including through regional, online, community-based and accessible consultation mechanisms
- publish regular plain English updates about its work, issues raised by carers and actions taken
- advise on culturally safe, trauma-informed and accessible engagement with diverse carer groups, and
- support whole-of-government coordination of carer recognition.

COTA Queensland supports maintaining specific representation for grandparents and grandparent carers. However, membership provisions should also ensure broader lived experience diversity, including older carers, Aboriginal and/or Torres Strait Islander carers, culturally diverse carers, rural and remote carers, LGBTIQA+ carers, carers of people living with dementia, carers of people living with disability or psychosocial disability, and carers with experience navigating aged care, health, disability, mental health and child safety systems.

Lived experience should be prioritised on QCAC with diversity of representation and mechanisms that support carers to participate without fear of reprisal or dismissal. It is also recommended that lived experience members be appropriately supported and remunerated with accessible meeting arrangements, clear induction, trauma-informed participation processes and support to engage meaningfully.

8. Regular review of the Act

COTA Queensland strongly supports embedding a mandatory periodic review of the Act.
The Act has not been substantially reviewed since commencement despite significant changes in Queensland's care landscape (including healthcare reforms, state and national care economies, NDIS and aged care reforms). A regular review mechanism would help ensure the Act remains contemporary, fit for purpose and responsive to emerging evidence, demographic change and lived experience. COTA Queensland recommends that *the Act be independently reviewed at least every five years*. Each review should consider whether:

- the Act remains compatible with the Human Rights Act 2019 and aligned with the Anti-Discrimination Act 1991
- the Act and Charter reflect the diversity of carers and care relationships

- public authorities are meeting their obligations
- monitoring and reporting mechanisms are effective
- carers are experiencing practical recognition in service settings
- QCAC is visible, accessible and effective
- lived experience participation is meaningful and representative
- the Act is improving outcomes for carers, and
- whether further legislative amendments are required.

The review process should include accessible consultation with carers across Queensland, including carers in rural, regional and remote communities, older carers, grandparent carers, Aboriginal and/or Torres Strait Islander carers, culturally diverse carers, LGBTIQA+ carers, carers living with disability or chronic health conditions, carers experiencing financial hardship or housing stress, and carers who may not self-identify as carers.

9. Future directions

COTA Queensland considers that the Act has provided a foundation for formal recognition of carers but has not sufficiently shifted system behaviour or community understanding. The review presents an important opportunity to uplift Queensland's approach to carer recognition. Carers need to be recognised as essential to Queensland's (health and social) care infrastructure, while also recognising that carers are individuals whose own lives, health, finances, housing, employment, relationships, social participation and wellbeing may be profoundly affected by their carer responsibilities.

Future reform needs to be guided by recognition that is:

- Practical - carers should see recognition reflected in intake processes, hospital discharge planning, aged care and disability service interactions, complaint handling, public authorities' reporting, staff training and service navigation.
- Accountable - authorities should be required to demonstrate how they identify, consult, include and support carers within the legislation and the Charter.
- Rights-based - carers should be recognised as people with their own rights, needs and aspirations (not only as a resource - as part of the care economy that sustains formal systems).
- Inclusive - the Act and Charter should explicitly recognise diverse care relationships and intersectional experiences.
- Informed by lived experience - carers must be involved early and meaningfully in the design, implementation, monitoring and review of policies and services that affect them.
- Be whole-of-government - caring intersects with health, aged care, disability, mental health, child safety, housing, transport, employment, justice, disaster response and community services. The Act should support coordinated recognition across these systems.

Recommendations

COTA Queensland presents seven overarching recommendations that have been identified through engagement with carers and advocates. The recommendations are presented as opportunities within implementation, monitoring and reporting of potential and future changes and reforms in care related legislation (inclusive of the Act and the Charter).

Table 2. Primary recommendations and considerations

Overarching recommendation	Intention of the recommendation
Recommendation 1: Establish a rights-based framework for carer recognition	Redevelop the Charter through stronger recognition of carers' rights, aspirations, economic security, and needs for wellbeing, participation, inclusion and support.
Recommendation 2: Improve recognition of diverse carers and care relationships	Broaden recognition of informal, kinship, older, grandparent, Aboriginal and/or Torres Strait Islander, culturally diverse, LGBTIQA+, rural and remote carers, including those who may not self-identify as carers.
Recommendation 3: Strengthen obligations on public authorities and relevant service systems	Require public authorities and relevant services to identify, consult, include and inform carers including through staff training and clear escalation pathways.
Recommendation 4: Improve service navigation and recognition of legal and practical care roles	Clarify legal authority and practical caregiving roles, reduce administrative duplication, and widely promote existing support services and carer navigation pathways.
Recommendation 5: Strengthen monitoring, reporting and accountability	Reintroduce reporting requirements, require public reporting on implementation, and establish independent oversight and evaluation.
Recommendation 6: Strengthen the Queensland Carers Advisory Council	Enable QCAC to monitor implementation, request information, provide public updates, improve visibility and strengthen lived experience diversity on QCAC.
Recommendation 7: Embed continuous review and improvement	Require independent review of the Act at least every five years with accessible consultation and assessment of outcomes for carers.

Recommendation 1: Establish a rights-based framework for carer recognition

Uplift of the Act and redevelopment of the Charter to reflect everyday care relationships and a rights-based approach to recognition by:

a. Redevelopment of the Queensland Carers Charter through a rights-based framework.
b. Adopting an approach that recognises both carers and the people they care for as individuals with rights, preferences, dignity and changing needs.
c. Strengthening the objects of the Act to recognise carers' rights, wellbeing, participation, inclusion and support needs, in addition to their social and economic contributions.
d. Recognising carers' wellbeing, including mental health, physical health, social participation, respite, financial security and community inclusion.

e. Recognising the economic consequences of caring including reduced workforce participation, loss of income, reduced superannuation and long-term impacts to retirement and later life.

Recommendation 2: Improve recognition of diverse carers and care relationships

The Queensland Government should ensure the Act reflects the diversity of care arrangements by:

a. Broadening recognition of diverse care relationships including informal carers, older carers, grandparents who undertake informal care, grandparent carers, kinship carers, parents caring for adult children with disability, Aboriginal and/or Torres Strait Islander carers, culturally diverse carers, LGBTIQA+ carers, rural and remote carers, and carers living with disability, chronic health conditions or changing capacities.
b. Updating the definition of carer and adopt a broader care relationship model that includes informal, kinship and culturally diverse family structures.
c. Expanding culturally safe, trauma-informed and regionally accessible engagement with carers across Queensland.
d. Improving awareness, outreach and recognition of carers including people who may not self-identify as carers.
e. Ensuring carers are recognised in emergency planning, disaster recovery and service continuity arrangements.

Recommendation 3: Strengthen obligations on public authorities and service systems

The Queensland Government should strengthen accountability for carer recognition by requiring public authorities and relevant service systems to:

a. Identify, recognise, consult and include carers in decisions, policies, programs and services that affect them.
b. Provide clear information to carers at key transition points including diagnosis, intake, assessment, hospital discharge, aged care entry, service review and crisis points.
c. Document carer consultation and involvement where decisions affect carers or the people they support.
d. Provide staff training on the Act, the Charter, human rights, privacy, consent, supportive decision-making, substitute decision-making and the practical role of carers.
e. Establish clear and accessible escalation pathways when carers are (or feel they are) excluded, ignored or not appropriately consulted.

Recommendation 4: Improve service navigation and recognition of legal and practical care roles

The Queensland Government should improve carers' interactions with service systems by:

a. Establishing clear procedures for recognising legal decision-making authority and distinguishing this from practical everyday caregiving roles.

b. Reducing administrative duplication for carers including repeated provision of the same documents within the same organisation or system.
c. Widely promoting carer information and navigation pathways to help carers understand their rights, roles, supports and complaint options. Examples include state government online hubs where support groups for carers are listed, Time for Grandparents, peak body Carers Queensland, and national platforms such as Carer Gateway.[7]

Recommendation 5: Strengthen monitoring, reporting and accountability

The Queensland Government should introduce stronger accountability mechanisms by:

a. Reintroducing monitoring and reporting requirements for public authorities, with stronger obligations for agencies and services that directly affect carers and care recipients.
b. Requiring public reporting on implementation of the Act and Charter including practical examples of how carer voices have influenced policy and service delivery.
c. Establishing independent oversight and evaluation mechanisms to assess implementation and outcomes.

Recommendation 6: Strengthen the Queensland Carers Advisory Council

Strengthen QCAC's role, visibility and effectiveness through consideration of the following:

a. Enable QCAC to request information, monitor implementation, provide public updates, identify systemic issues and advise government on compliance and reform.
b. Improve QCAC's visibility and accessibility through public communication, regional engagement, online engagement and clear pathways for carers to raise issues.
c. Maintain grandparent carer representation while strengthening the diversity of lived experience representation on QCAC.
d. Ensure lived experience members of QCAC and other advisory mechanisms are appropriately remunerated, supported and enabled to participate safely and meaningfully.

Recommendation 7: Embed continuous review and improvement

Ensure the legislation remains contemporary and adaptable (aligns broadly with healthcare, NDIS and aged care landscapes) and effective through:

a. Embedding mandatory independent review of the Act at least every five years.
b. Requiring each review to assess implementation, accountability mechanisms, lived experience participation, diversity and inclusion, and outcomes for carers.
c. Ensuring future reviews include accessible consultation with carers across Queensland.

[7] Australian Government. (n.d.). *Carer Gateway* [Website]. https://www.carergateway.gov.au/
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The review of the *Carers (Recognition) Act 2008* (Qld) presents an important opportunity to uplift the carer recognition framework to one grounded in rights, participation and inclusion. While the current Act and the Charter have provided a critical foundation for recognition of carers, lived experience insights indicate that this has not translated into recognition in practice.

Carers across Queensland provide essential unpaid support that enables health, aged care, disability, mental health, child safety and community service systems to function. Yet many continue to experience exclusion from decision-making, poor communication, limited information, administrative burden, inadequate respite, financial insecurity, isolation and burnout. Recognition must therefore become practical and accountable with diverse carers identified, listened to, informed and respected as partners in care across hospitals, aged care, disability services, government agencies and community settings.

There is a need to strengthen obligations from public authorities, reintroduce transparent monitoring and reporting, embed lived experience in policy and service design, and recognise the diversity of care relationships. A strengthened Act and redeveloped Charter would ensure carers are recognised for the care they provide *and* as people with their own rights, wellbeing, support needs and futures. Carers should not be left to navigate complex and fragmented systems alone or at the cost of their own health, financial security and social participation. Queensland has an opportunity to lead with an inclusive, accountable and stronger framework that delivers meaningful change for all carers across the state.

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