



DEPARTMENT OF DISABILITY, HOUSING AND COMMUNITY SERVICES

DEVELOPMENT OF A CARERS CHARTER

COMMUNITY CONSULTATIONS

REPORT

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Executive Summary

Contributions to the Department of Disability, Housing and Community Services' (DHCS) Carers Charter consultation process were received from a diverse range of carers and this ensured that the process was robust and well informed.

A key message from participants in the workshops and through submissions is that the Charter must operate as one component in a broader strategy to achieve positive change for carers. The existence of the Charter does not in itself guarantee progress, although it is a useful first step. To be meaningful in practical terms, the promises in the Charter must be integrated with progressive policies and processes if it is to be a successful addition to the caring communities' suite of initiatives.

Carers are keen to see the work of the ACT government and community in this area align with national strategic developments. Linked to this, the consultation process highlighted the importance of national consistency where appropriate, including for statistical purposes and evaluation.

"Like water on a stone, the charter is part of long term action to achieve attitudinal change. The fact that DHCS is investing the resources in this project indicates a commitment by government to a charter. The symbolism of the process is important."

Workshop Participant

Consideration of the definition of a carer evinced significant differences of view, although most discussions concluded that this was something of a distraction from the Charter itself. The additional contextual/explanatory information associated with the one-line definition provided in the DHCS discussion paper was noted as being useful in this regard and could potentially be included in future documentation as the Charter is implemented.

As a result of the consultation process, *Louise Gray Consulting Services* proposes amendments to the current wording of the Carers Charter. These amendments are shown at [Attachment C](#). As the changes indicate, the consultations indicated a broad acceptance of an inclusive Charter as being a useful platform for the future directions of policy and support for carers in their caring role.

Background and Issues

More than 2.7 million Australians provide care for family members or friends. One in every eight Australians has taken on a caring role. Carers provide unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness or who are frail aged.

Carers come from all walks of Australian society and enter the caring journey at various stages throughout their life. Identifying and meeting the needs of carers, given the diversity of their circumstances, is complex and challenging.

A 2007 survey into the health and well-being of Australian carers, undertaken by Deakin University, Australian Unity and Carers Australia showed carers to have the lowest collective well-being of any group yet identified. These findings showed the importance of understanding what supports are effective in improving outcomes for carers and, as such, placed the longitudinal evaluation of well-being firmly on the agenda for Australian governments at both federal and State/Territory levels.

- In 2006, the *Carers Recognition Legislation Amendment Act* was introduced.
- In 2008, the ACT Government made a commitment to develop an ACT Carers Charter.
- In 2010, the federal government is progressing a National Carer Strategy.

Governments within Australia and around the world recognise the important role which carers play in providing a vital service to the community.

"All carers give of themselves, their time and limited resources should be recognised."

Foster Carer

Methodology

The nature of caring is such that carers cover a diverse mix of different people, all experiencing different social, economic and other lifestyle circumstances. In order to maximise the opportunities for carers to contribute to the development of a Carers Charter in the ACT, a range of different consultation methods were used. These included the following:

- Five community consultation workshops were organised for various different times of the day and held in both north and south Canberra locations close to bus lines. Workshops focused on gaining insights from the following groups:
 - All carers;
 - Older carers;
 - Young carers and young adult carers; and
 - Foster, kinship and grandparent carers.
- A general call for participation in workshops was advertised on:
 - the CDNet community email distribution list;
 - the ACT Government Community Engagement calendar;
 - the DHCS website;
 - community peak body websites and newsletters.
- Specific letters of invitation to participate in workshops were sent to peak bodies, community stakeholders and a number of other groups.
- The workshops were advertised in:
 - The Canberra Times;
 - The Canberra Chronicle;
 - The Queanbeyan Age;
 - The DHCS Multicultural Newsletter.
- The ACT Aboriginal and Torres Strait Islander Elected Body was represented at all workshops and Aunty Agnes Shea OAM, Ngunnawal Elder, provided a welcome to country at each session.
- To support consultation with Culturally and Linguistically Diverse carers, the Carers ACT CALD Carers Programme was contacted. Representatives of the National Ethnic Disability Alliance (NEDA), the ACT Chinese Australian Association and the Canberra Multicultural Community Forum participated in the consultation forums.
- Carers ACT assisted in raising awareness of the consultation process via their website as well as direct emails to carers registered with them. Carers ACT also highlighted the process at their own Annual General Meeting.
- To support consultation with young carers and young adult carers, the Youth Coalition was contacted.

- Written submissions were invited to be made directly to DHCS by 31 January 2011.
- *Louise Gray Consulting Services* invited carers to contact their consultants via telephone or email if they wished to provide input outside the workshop environment. Several individuals did so.
- The consultation process was announced via a media release from the ACT Minister for Disability, Housing and Community Services, Ms Joy Burch MLA.

Approach and Discussion

The focus of all consultative methods used in the project was to identify common areas of interest and concern for carers in the ACT to ensure that the Charter reflects the diverse range of views held across the caring community. Building on these shared areas of interest, the consultation process sought to determine the role which a Charter might play in the Canberra community, including how it might be implemented in practice for carers, community service providers, government entities and other stakeholders.

The series of workshops was a key strategy for gathering community views on the proposed Carers Charter. To ensure all participants had a shared level of understanding of the background to the development of the Charter, information was provided regarding the Carer Recognition legislation which has been enacted in many Australian States/Territories, the federal carers Recognition Bill 2010 and the National Carer Strategy which represents the second element of the National Carer Recognition Framework. In 2006, the Carer Recognition Legislation Act represented the ACT government's commitment to the critical role which carers play in the community. Building on this, the workshop drew out discussion around the purpose for developing a Carers Charter, highlighting its role in supporting:

- clarity and standards around how carers are treated and how they should expect to be treated by government and community service providers;
- individual needs of carers;
- information to support carers in their caring role;
- quality improvement;
- awareness raising, both for carers in terms of resources available and for the community in respect of the role which carers play;
- the reduction of systemic barriers.

Practical outcomes of having a Carers Charter were presented to workshop participants, including:

- reflecting the values of the Charter in client service standards and codes of conduct;
- leading to training and service development; and
- ensuring that suggestions and complaints are addressed in an appropriate and timely manner.

Each workshop reviewed the components of the draft Charter and discussed gaps and priorities. Implementation of the Charter was also a focus for discussion, including how this might be managed and the expected roles and impact for carers, government and service providers.

The discussion questions provided in the *Discussion Paper and Proposed Charter* document issued by DHCS in October 2010 provided a useful framework for focusing what are often emotional issues linked to a challenging and often unrecognised role. While not all discussion questions were addressed in full, there was sufficient feedback across all workshops to broadly address them.

Discussion Questions:

- Would an inclusive Charter appropriately represent the rights and needs of all Carers in the ACT?
- Are other mechanisms necessary to support caring relationships that may not be identified by the Caring for Carers Policy or Foster Carers and Kinship Carers Guide?

There was a strong consensus that inclusiveness is a principle which should be a goal in key framework tools such as a charter. Proposed amendments to wording, as incorporated in the revised draft at Attachment C, were suggested to reduce the risk of unintended restriction of the charter to specific groups. That is, there was a sense that the specification of certain groups of carer implied the exclusion of others. The only exception to this related to Aboriginal and Torres Strait Islander carers, who were seen as disadvantaged to such a degree as to warrant specific mention.

The need for constant review of the mechanisms, programmes and tools which exist to support carers and caring relationships was considered important, especially noting that the ageing population is likely to drive a shift in the type and availability of services for carers. As such, it was generally agreed that other mechanisms beyond those identified in the Caring for Carers Policy or Foster Carers and Kinship Carers Guide will continue to be important.

Discussion Questions:

- Does the definition of "Carers" adequately reflect all carers in the ACT?
- Is an inclusive definition of "Carers" appropriate given the diverse nature of the caring role?

Participants were invited to discuss the definition of a carer as proposed in the DHCS discussion paper in light of the different approach of the Australian Government's Carer Recognition Bill. Discussion was extensive regarding the benefits of an inclusive and broad definition versus a more targeted definition. Foster care, in particular, drew significant debate as to its appropriateness for inclusion due to the payment of some funds to foster carers to meet a portion of the costs incurred when providing foster care. For the purposes of a charter, the importance of inclusiveness was considered to outweigh these concerns, although it was noted as an issue to be considered when progressing future policy directions.

A carer is a person who provides unpaid primary care to someone else who is dependent on the person for ongoing care and assistance’.

Proposed definition of a carer for inclusion in the ACT Carers Charter

There was a degree of apprehension as to whether a broader definition would open up eligibility for scarce programme funds set aside for the support of carers. On balance, discussion indicated that the more inclusive approach was preferable and that any risk of dilution of service availability by broadening the definition would be better addressed at the policy and programme development level. This was also considered to be in keeping with the earlier discussion about preference for an inclusive charter.

Discussion Questions:

- Is there adequate awareness of legislative rights for Carers in the ACT?

The need for increased awareness of legislative right for Carers in the ACT was linked to a discussion about the need for improved awareness generally as to the role of carers, particularly in the health care, education and community services sectors.

Some carers expressed frustration at the lack of awareness on the part of health practitioners as to the caring role, noting that many fail to take into account the experience and advice of the carer when considering the diagnosis and treatment of the person receiving care. Worse, young carers reported being required to leave the treatment room during consultation despite being the carers ultimately responsible for implementing the treatment regime. A sense of wanting to be taken seriously and respected as a key stakeholder in the management of the care of the person for whom they care coloured this discussion.

The seeming inequity of the rights of grandparent and kinship carers was discussed in comparison with the rights of foster carers. Grandparent carers expressed frustration at the inability of the legislative framework to allow for the often cyclical care which they provide. For example, if they care for their grandchild when the child’s parent is struggling with substance abuse, this caring role may not be legally recognised. Further, they wished to better understand their rights to retain the caring role if the parent wishes to regain full care but is still abusing drugs or alcohol and, as such, may not be able to do so.

In summary, the legislative rights of carers would benefit from increased prominence, particularly in the communities and sectors which provide services and support to them.

Discussion Questions:

- What steps are needed for organisations to implement the Charter?

Discussion Questions:

- Are any other measures necessary to ensure the successful implementation of the *ACT Carers Charter*?

The Charter as a basis for awareness raising was discussed as a key early function in progressing government policy for carers while also driving reform in the human services sector. In essence, if it could be seen as a platform for the development of policy responses and programme development, this would flow through to its effective implementation as a tool designed to set the framework for future directions.

Many workshop participants expressed the view that the public display of the Charter in key services and locations would act as an assurance to carers accessing those services that they could expect awareness and understanding of their caring role. Further, the increased role of nurse practitioners in ACT primary health service provision and the establishment of Medicare Local outlets may present an opportunity to ensure that carers and the caring role are fundamental considerations when providing services.

"This cannot be just a glossy piece of paper which makes everyone feel good but achieves nothing in practice. The Charter has to lead to action to better support carers in Canberra."

Mother caring for a son with mental health issues

There was some degree of scepticism about the degree of change which is likely to arise from the Charter itself, with strong agreement that it needs to be part of wider reform. As such, the use of the Charter as a framework document upon which policies and programmes could be based is an important concept moving forward. Building on this, there was also a push for service providers to be accountable for operating within the parameters of the Charter, for example by being subject to evaluation to ensure that they are implementing the Charter appropriately. This could be as simple as requiring them to display the charter through to including it as part of any service or funding agreements.

Feedback from Workshops

All Carers

Key Points:

1. The Charter must be seen as part of a wider process of reform. Implementation will be critical.
2. Because this is not a rights based charter, there is a risk that it will not be taken seriously or really influence change in practical terms.
3. The broader community does not understand the caring role. The Carers Charter presents an opportunity to raise awareness.
4. Caution must be taken when seeking to separately identify any particular carer groups.

Two workshops for all carers were held. The session of 17 November 2010 attracted 15 participants while the session of 6 December 2010 attracted around 25. The diverse individual circumstances of those in attendance meant that discussion was broad ranging and contributed a number of useful points as the Carers Charter is further developed and implemented.

Above all, the Charter was seen as a stepping stone to reform. The importance of linking in with national projects and initiatives was highlighted, noting that aligning approaches nationally would aid future collaboration and influence federal policy agendas. The Charter is also a means of ensuring that carers do not fall through the gaps of an increasingly complex policy environment.

The need to raise awareness of the caring role in the broader community was seen as a key aspect of progressing the Charter. Participants noted that people often do not understand or appreciate the caring role until they are themselves caring or receiving care.

The specific references to particular groups in the charter was discussed to a considerable degree with concerns being raised that the inclusion of those groups may be seen as therefore excluding other groups. While Aboriginal and Torres Strait Islander carers were recognised as requiring particular focus, there was a reluctance to single out other groups. Instead, there was a strong view that all carers should be afforded the same rights, respect and access to support.

While discussion around the definition of carers was extensive, it was ultimately seen as something of a distraction as any definition needs to be read in the context of related strategies. To this end, the additional contextual/explanatory information in the DHCS discussion paper was seen as valuable in supporting wider understanding of the definition of a carer.

The inclusion of foster carers evoked considerable discussion. Some participants raised concerns that foster carers may now expect the same access to support services as other carers and that this may place a risk on the resources available. There was also some discussion around the differences between kinship care and foster care as essentially an alternative parenting role.

Again in relation to the definition, the reference to primary carers was seen as not reflecting the role of secondary or co-carers, siblings and carers who are deemed too young to be recognised.

Several participants noted that, in the case of older carers, sometimes both parties need care. For example, a 70 year old may be caring for a 90 year old and may also have his/her own caring needs. Older carers from Culturally and Linguistically Diverse backgrounds face additional challenges if the person they care for reverts to their language of origin, complicating their care needs. Providing support to carers in such circumstances requires understanding and real knowledge, not just awareness.

“Indigenous Australians are recognised as a dying race in a wealthy country. As such, it is appropriate that they be distinguished as requiring particular focus in the document.”

Ngunnawal Elder

Older Carers

Key Points:

1. Older carers often neglect their own needs as they age because the focus is on the person for whom they care.
2. The experience and expertise of carers should be recognised by service providers and health care practitioners.

A workshop for older carers was held on 17 November 2010. Eight people attended, including three individuals caring for a family member, two DHCS staff and three representatives of community organisations.

Older carers noted that they often do not consider their own needs as they age because their focus is on the impact which their ageing has on the person for whom they are caring. This can have impacts across:

- financial planning and planning for retirement;
- health needs, such as deferral of treatment for medical conditions due to concerns about who will provide care in the carer's absence;
- guardianship and establishment of the legal framework to support the

care recipient should the carer become unable to provide care.

The cultural considerations for specific carers were discussed in some detail, noting that this is not always supported by service models available. For example, respite care which separates the carer from the care recipient can actually increase stress. Flexible options were seen as important in reflecting the different cultural expectations which exist, especially for those caring for aged parents.

Participants noted how important it is that respect and dignity does not lead to patronisation. When dealing with service providers in the health, community and education sectors, it is important to encourage a culture which ensures that what carers have to say will be taken seriously and not dismissed as “just another neurotic carer.” It is important that what carers have to offer is valued and that service providers see working with carers as an important and shared contribution. Linked to this, staff in government and community organisations should be accountable for their actions.

“Some older people from other nationalities revert to their language of origin as they age. But it is not enough to simply provide a translator when seeking medical services. There needs to be more done to understand and work with the different cultures to ensure that carers and the people they support are able to access services.”

CALD carer

Access to information via medical professionals can be difficult and would be helped by access to a “one stop shop” post diagnosis of medical issues. For example, the Alzheimer's support groups are considered to be extremely valuable to carers and this experience is similar across other areas, including mental health and substance abuse.

“I don't think it should be modified because that is exactly what I do.”

Woman caring for her mother with Alzheimers when asked whether the proposed definition of a carer should be altered

Young Carers and Young Adult Carers

Key Points:

1. Young carers must be taken seriously as key stakeholders in managing the support needs of the person for whom they care, even if they are not the primary carer.
2. Linkages across government portfolios are key to ensuring that young carers' needs are met. This includes health, community services, education, housing and more.

Young carers experience very different challenges as they seek to balance their schooling, social and other commitments which form part of the transition from childhood to adulthood. The idea of "ongoing" care provision is problematic for inclusion in the definition as so many young carers provide episodic care.

The group discussed what was intended by the use of the term "primary" in the charter. Confusion may be possible especially given "primary health care" is a definition itself and the term may be different in a legislative context than in a charter. Having depth of definitions somehow linked to the Charter might help change awareness of the diverse types of carers and care needs.

As well as having a right to information and services for themselves, carers have a right to access to information and services for the person they care for. This includes being involved with the development of the person's care plan. For young carers, who are not necessarily taken seriously by service providers, this is a particular concern.

The group strongly believed that raising awareness of the caring role through having a Charter is important. Identifying what carers need is a possible outcome of this awareness and would help ensure that this leads to action and real change, rather than being just a statement of intent.

Going beyond the Charter, the group discussed the need to tailor services to what young carers want. This might include being more flexible about respite opportunities and school arrangements and working with the carers rather than dictating arbitrary decisions. Young carers often do not identify as such because of a sense of shame or because it has become normalised because so many members of the family have drug and alcohol and/or mental health issues.

Young carers require more support, and flexible support, to meet their caring role needs. For example, the Public Trustee and Public Advocate should be more available to play a role in supporting young carers on legal and financial issues. Improving access to schools for youth workers and advocates may be a good way to support the practical application of the charter to young carers.

"Because of my age, I am not taken seriously by doctors and pharmacists even though I am my mother's primary carer. I need to know about her health so I can care for my mother but the GP asks me to wait outside during appointments."

Young carer

Grandparent, Foster and Kinship Carers

Key Points:

1. The Child Protection Framework is under development. DHCS should ensure that the process is appropriately linked to the Carers Charter.
2. The inclusion of foster carers in the definition of carers is the subject of considerable debate.

The ACT Carer Recognition Legislation Amendment Act 2006 is particularly important to this group as it allowed for the inclusion of foster, kinship and grandparent carers. The group discussed and welcomed the new counselling service for kinship carers in the ACT, which was announced by the Minister for Children and Young People in November 2010.

The inclusion of foster carers or 'statutory carers' as recognised carers was a point of considerable debate. While some believe they should be included as the financial contribution made by government towards their caring role is not recognised as income and, indeed, does not cover the costs of care, others were of the view that they should not be included as foster carers choose to care while other carers do not. This also places a tension on the government's formal legal role as surrogate parent.

"Yes, foster carers get an allowance but it is not counted as income and does not cover the full costs of care and is it any different to the Carers Allowance? The exclusion of foster carers from this sort of document would be a significant concern."

Foster carer

Guardianship issues and legal rights come to the fore when a grandparent is assisting the parents in providing care. They may not legally be seen as the primary carer and this can impact on their capacity to access support. While the Charter itself was not seen as a means of resolving this, the point was considered relevant as a fundamental issue for defining who carers actually are.

Access to information was noted as a key consideration when seeking to provide care. Several people noted that, once they had accessed the care and support “system” they were able to find the services required but, until that point, they did not have a sense of what was available or which organisations to contact. The need for general practitioners to assist in disseminating information for carers was highlighted.

Linked to the Charter, participants were keen to see a robust appeals system implemented to ensure that carers can access advocacy support and assurance without fear of retribution.

“... grandparent carers have less rights and are subjected to more scrutiny than foster carers when they wish to simply include the young person they care for in their family activities and holidays. Where the relationship with the parent has broken down, grandparents are at the mercy of 'the system'.”

Grandparent carer

Submissions

In addition to the workshops, fourteen submissions were received as part of the consultation process, representing a variety of different carer groups and perspectives.

- A list of submissions is provided at Attachment B.

Key points raised in the submissions include:

- The need to build on and ensure consistency with national work to date, the National Carer Recognition Framework and the legislative framework first established in 2006 with the *Carers Recognition Legislation* Amendment.
- The need to define who is included in the definition of a carer and apply access to supports consistently, eg: including young carers in the *Caring for Carers* policy.
- The need for structures and processes to ensure compliance with the principles espoused by the Charter, including through links to funding agreements and appropriate monitoring, reporting and evaluation
- The need for carers to be seen as legitimate and contributing members of the caring team, particularly when dealing with health care professionals
- The importance of recognising and responding to the specific needs of different carers, including where a carer may need care themselves and noting, where relevant, gender-related variations in experience.
- The need for actual change in practical terms, including ensuring that the Carers Charter is more than simply a glossy publication to which carers and service providers do not actually refer.

"... there are more important issues to be addressed than a Carers Charter."

Autism Asperger ACT

Recommendations

As a result of the consultation process undertaken through this project, it is recommended that:

- the ACT Carers Charter be amended as per Attachment C.
- the future implementation of the Carers Charter be linked to national work in this area.
- the Carers Charter be used as a key awareness raising tool to support broader understanding of the caring role and associated service needs, including through dissemination to key community stakeholders including schools and general practitioners.
- A range of implementation and evaluation measures be developed to ensure that it is actively and consistently referenced and applied by service providers in the community, health and education sectors.

References

ACT Department of Disability, Housing and Community Services, *ACT Carers Charter Discussion Paper and Proposed Charter*, October 2010

Australian Government, *Carers Recognition Legislation Amendment Act*, 2006

ACT Department of Disability, Housing and Community Services, *ACT Charter of Rights for Children and Young People in Out of Home Care*

ACT Department of Disability, Housing and Community Services, *ACT Homelessness Charter*

Gray, Louise, *National Carer Counselling Programme Report*, June 2010

Carers Charters from other Australian jurisdictions and international comparisons

List of Submissions Received

Submissions were received from a number of individuals and organisations. Not all individuals wished to be named in this report. Submissions were received from:

- five individual carers.
- one person who receives care.
- eight organisations:
 - Autism Asperger ACT;
 - Cancer Council ACT;
 - Anglicare Canberra and Goulburn;
 - Youth Coalition of the ACT;
 - Carers ACT;
 - Women's Centre for Health Matters;
 - Foster Care Association of the ACT;
 - Women With Disabilities ACT.

Revised Draft Carers Charter

Based on the consultation process, the following wording is proposed:

1. Carers are engaged in the assessment, planning, delivery and review of relevant services that affect them in their caring role.
2. Carers views and needs are taken into account when relevant decisions are made that affect them in their caring role.
3. Carers are valued and treated with respect and dignity.
4. Carers are offered appropriate and timely information on the support services available to them.
5. Aboriginal and Torres Strait Islander carers and co-carers are offered appropriate and timely access to supports that recognise their individual needs.
6. Recognising that older carers, young carers, young adult carers, foster carers, kinship carers, grandparent carers and culturally and linguistically diverse carers have particular needs, all carers are offered appropriate and timely access to supports that recognise these needs.
7. The importance of social inclusion for carers and the people for whom they care is recognised and supported.
8. Carers' suggestions in relation to services that affect them in their caring role are responded to appropriately and in a timely manner.