



**Carers Australia Submission on the User Rights Principles 2014  
Exposure Draft**

**May 2014**

Carers Australia is the national peak body representing the diversity of Australians who provide unpaid care and support to family members and friends with a:

- disability
- chronic condition
- mental illness or disorder
- drug or alcohol problem
- terminal illness
- or who are frail aged.

Carers Australia believes all carers, regardless of their cultural and linguistic differences, age, disability, religion, socioeconomic status, gender identification and geographical location should have the same rights, choices and opportunities as other Australians.

They should be able to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment and education.

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## Introduction

Carers Australia welcomes the opportunity to comment on the exposure draft for the User Rights Principles 2014.

Care provided by family and friends is the backbone of Australia's home care system, including aged care at home. Family and friend carers also make significant contributions to the lives of residents in aged care facilities. In recognition of this role of carers, the *Carers Recognition Act 2010* specifies in point seven of its ten point Statement for Australia's Carers:

*7. Carers should be regarded as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers.*

This Statement is complemented by a National Carer Strategy with six priority areas for action which include recognition and respect for carers and a policy direction to strengthen awareness and understanding of their role.

The draft User Rights Principles 2014 under section 96 (1) of the *Aged Care Act* are aligned with both the substantial shift in delivery of aged care services towards more person centred models of care and, to some extent, increased recognition of the role of carers in supporting older people at home and in residential care.

We are pleased to note that section 5 of the User Rights Principles 2014 Exposure Draft features a new expanded definition of "representatives" of service users. It now reflects the important priorities of acknowledging family and other carers as well as representatives who have a formal enduring power of attorney or who have been appointed by a state or territory guardianship board. This change will make it easier for carers to stay informed about and involved in matters involving the care of the care recipient.

However, family members, other carers and those they care for will only be able to reap the benefits of this new definition if the instrument also specifies the occasions in which the definition can be applied in practice.

## Issues

The 2011 version of the User Rights Principles contains 26 references to "representatives", of which 24 are of direct relevance to family members and other carers. Nine of these references pertain to financial matters and we understand these matters will be transferred into the Aged Care (Transitional Provisions) Principles 2014.

The remaining 15 provisions established other rights for family members and other informal carers of people in residential care and home care.

Key deleted provisions from the 2011 User Rights Principles include:

- The rights of representatives to participate in the choice of a medical or other health practitioner assessing the care recipient (sections 23.5 (4) (b), 23.6 and 23.15)

- The rights of representatives to receive information about the care recipients rights and obligations (sections 23.14 (1) and (2) as well as 23.26 (1))
- The rights of representatives to be given a statement of audited accounts by the provider (section 23.17)
- The right of representatives to ask a person acting for an authorised body to assist the care recipient and for such a person to have access to the provider's home care service (section 23.23).

These principles are applicable to both residential and home care settings.

With respect to residential care, family and friend carers can and often do contribute to both the quality of care. Research undertaken by Carers Australia and its associations and by a number of health consumer groups has identified that the continuing involvement of family and friend carers in residential settings can offer the following benefits (among others):

- allows the continuity of relationships with family members or lifelong friends
- maintains the emotional health and wellbeing of residents
- can assist in reducing depression which affects between 30% and 50% of residents
- contributes to the quality of care to the extent that informal carers have acquired expertise on how to care for the individuals through in-depth knowledge of their medical history and care preferences
- fills service gaps in the provision of residential care (particularly important in the case of CALD and Aboriginal and Torres Strait Islanders).

## Recommendations

The changes recommended below to restore the explicit rights of representatives embodied in the User Rights Principles 2011 were observed in the new instrument and ensure that the of the Aged Care Act will be consistent with the principles of the Carer Recognition Act, and provide additional substance to the implementation of the priorities contained the National Carer Strategy.

### (1) Reinstatement of the User Rights Principles 2011 relating to representatives

In order to ensure the continuation of the rights of family members and other informal carers which were established in the 2011 User Rights Principles, we recommend the following amendments to the User Rights Principles 2014 (proposed changes are underlined):

- Section 7 (4) (b) (i) (relating to the requirement for 2 medical or other health practitioners) to be amended as follows:
  - (i) *one must be independent of the approved provider and the residential care service and must be chosen by the care recipient or his or her representative.*
- Section 11 (2) (a) (relating to the requirement for 2 medical or other health practitioners) to be amended as follows:
  - (a) *one practitioner must be independent of the approved provider and the residential care service, and must be chosen by the care recipient or his or her representative.*
- Section 12 (relating to information rights and responsibilities) to be amended as follows:
  - (1) *An approved provider of a residential care service must give a care recipient or his or her representative information about:*
    - (a) *[same as in the Exposure Draft]*
    - (b) *[same as in the Exposure Draft]*
    - (2) *[same as in the Exposure Draft]*
    - (3) *the approved provider must assist the care recipient or his or her representative to understand the information.*
- Section 13 (1) (relating to the statement of audited accounts) to be amended as follows:
  - (1) *If Division 5 (Disclosure Standard) of Part 5 of the Fees and Payments Principles does not apply to the approved provider of a residential care service, the provider must, if asked, give a care recipient or his or her representative a copy of:*

(a) [same as in the Exposure Draft]

(b) [same as in the Exposure Draft]

- Section 13 (2) (b) (relating to the statement of audited accounts) to be amended as follows:

*(b) the approved provider gives the care recipient or his or her representative a copy of the most recent audited financial report prepared under that Subdivision.*

- Section 19 (relating to access to home care services by advocates) to be amended as follows.

*For paragraph 56-2(j) of the Act, an approved provider of a home care service must allow a person acting as an advocate for a body that has been paid an advocacy grant access to the provider's home care service. This advocate may be nominated by the care recipient or his or her representative.*

- Section 21 (relating to information about rights and responsibilities given by a home care provider) to be amended as follows:

*(1) An approved provider of a home care service must give a prospective care recipient or their representative information about the rights and responsibilities of the care recipient and provider, including the care recipient's rights and responsibilities, about the payment of home care fees.*

*(2) [same as in the Exposure Draft]*

*(3) The approved provider must assist the care recipient or his or her representative to understand the information.*

## **(2) New recommended requirement to be added to Part 4**

We also recommend that the User Rights Principles should make reference to the Carers Recognition Act 2012. This could perhaps be included as an addition under Part 4 – Miscellaneous:

*Approved providers should observe the Carer Recognition Act 2010 and acknowledge informal carers as partners in care.*

## **(3) Amendments to Schedule 1 and 2 Charters**

- In order to ensure greater consistency between the instruments of the Aged Care Act 1997 and the Carer Recognition Act 2010 and to define the responsibilities of family and friend carers toward paid carers we also recommend the following amendments to the **Charter of care recipients' rights and responsibilities - residential care (Schedule 1)**

- Section 1:

*Each care recipient has the following rights:*

*(a) – (t): [same as in the Exposure Draft]*

*(u) to be free from reprisal in any form for action being taken by the care recipient or his or her representatives to enforce his or her rights.*

*(v) to have his or her representative participate in decision relating to his or her care if he or she does not have capacity.*

- Section 2: Care recipients responsibilities - residential care

Each of the rights and responsibilities toward formal care workers should be amended to include that representatives share the responsibilities of care recipients.

- In order to ensure greater consistency between the instruments of the Aged Care Act 1997 and the Carer Recognition Act 2010 and to define the responsibilities of family and friend carers toward paid carers we also recommend the following amendments to the **Charter of care recipients' rights and responsibilities - home care**

- Section 1: Charter of care recipients' rights and responsibilities – home care

1 (6) *Comments and complaints* to be amended as follows:

*(6) Each care recipient and his or her representative have the following rights:*

*(a) to be given information on how to make comments and complaints about the care and services he or she receives*

*(b) to complain about the care and services he or she receives*

*(c) to have complaints investigated fairly and confidentially, and to have appropriate steps taken to resolve issues of concern.*

- Section 2:

Each of the rights and responsibilities toward formal care workers should be amended to include that representatives share the responsibilities of care recipients.