

10 October 2018

Submission: Draft Charter of Aged Care Rights

General comments about the draft Charter

Draft Charter – Preamble

The Australian Charter of Aged Care Rights (the Charter) helps to create a shared understanding about the rights of people receiving Commonwealth subsidised aged care. Having a shared understanding between people receiving care, their family, friends and carers, and aged care providers and their staff, helps everyone work together to achieve safe and high quality aged care.

The rights described in this Charter sit alongside other laws that inform the delivery and quality of aged care, for example the broader Aged Care Act 1997, the consumer outcomes in the new Aged Care Quality Standards, and rights under the Australian Consumer Law and anti-discrimination law.

The Charter helps people receiving care understand how their aged care provider will work with them. It also helps people receiving care understand how they will engage with others involved in their aged care service – so that they can enjoy the same rights. Sometimes aged care providers may have to balance competing rights. Providers will work to resolve these situations sensitively through consultation and with the spirit of the Charter in mind.

Draft Charter of Aged Care Rights

I have the right to:

- a) receive safe and high quality care and services
- b) be treated with dignity and respect and to have my individuality valued
- c) have my identity, culture and diversity valued and supported
- d) maintain my independence
- e) live without abuse and neglect
- f) be informed about my care in a way that meets my needs, have access to information about my rights, care, accommodation and anything else that relates to me personally, and get the information I need in a timely way
- g) maintain control over, and continue to make decisions about, my care and personal and social life
- h) be listened to and understood
- i) choose to have another person speak on my behalf
- j) complain, and to have my complaints dealt with fairly and promptly
- k) exercise my rights without it adversely affecting the way I am treated
- l) personal privacy and to have my personal information kept confidential

The Department seeks your comments on the draft Charter. We are particularly interested in your comments on the following:

12 Does the Charter cover what you think is important?

No

If no, please specify:

We commend the department for planning a Charter of rights and seeking feedback on the basic principles for this. What has been supplied is an information document setting out principles rather than a legal document that can be readily enforced in law. It needs to be supported by a legal document that is much more specific and which can be included in a contract with the provider.

The current regulatory framework does not provide a readily accessible pathway into the legal system and that should be addressed.

The right to appoint someone to examine documents and oversee your care and intercede on your behalf should be explicitly expressed.

This is particularly important in the current situation where a humanitarian service based on community has been turned into a market based on commercial considerations.

Large numbers of residents have been harmed. The media is describing abuse and neglect. Too often profit has clearly become more important than care. Predatory practices taking advantage of the vulnerable are also a feature of the marketplace in multiple other sectors indicating a systemic problem in the way markets have been introduced and managed.

13 Does the introduction/preamble require clarification or any further information?

Yes

If yes, please provide details

The preamble is adequate for an explanatory brochure describing principles but as such needs to indicate what resources are available for enforcement of non-compliance. It needs to be supported with a legally written document that is more specific and indicates what is required more specifically and this needs to be included in contracts to facilitate legal enforcement.

14 Should the Charter be phrased in the first person, 'I have the right to' or 'you have the right to'? Please select only one item

You have the right to

15 Are the rights in the draft Charter easy to understand?

Yes

16 Would you add any additional rights to the Charter?

Yes

If so, please provide details

That you, or if you are incapacitated the person/people responsible for you, will be able to appoint another person, persons or organisation to have access to all information in the provider's possession about you and your care including any personal information.

18 Would you change any rights in the draft Charter?

Yes

If yes, please specify which right and your suggested changes

If this is to be a substitute for a proper legally phrased Charter than can be used to obtain legal enforcement and/or redress, then we suggest the following changes that make it more inclusive.

If these are to be rights that can be enforced rather than an information brochure then advice should be sought from the ALRC (Australian Law Reform Council):

- a) receive safe and high quality care and **services ADD (without exploitation, discrimination or victimisation)**
- b) be treated with dignity and respect and to have my individuality valued
- c) have my identity, **ADD (Religious practices,)** culture and diversity valued and supported
- d) maintain my independence **ADD (including the freedom to move freely within and outside my place of residence and to be involved in activities; all without unnecessary restrictions)**
- e) live without abuse, neglect **ADD (exploitation, discrimination or victimization)**
- f) be informed about my care in a way that meets my needs, have access to information **ADD (and be consulted)** about my rights, care, accommodation, **ADD (living arrangements)** and anything else that relates to me personally, and get the information I need in a timely way
- g) **ADD (assume responsibility for my actions and the risks I take and so)** maintain control over, and continue to make decisions about, **ADD (my possessions,)** my care and personal and social life.
- h) **ADD (freedom of speech, and to)** be listened to and understood
- i) **DELETE (choose to have another person speak on my behalf)** **ADD (appoint another person, persons or organisation of my choice to have access to all information about me and my care including any personal information and then advocate on my behalf. If I am incapacitated the person/people responsible for me will have the right to make this appointment.)**
- j) complain, and to have my complaints dealt with fairly and promptly **ADD (without any fear of reprisal)**
- k) exercise my rights without it adversely affecting the way I am treated
- l) personal privacy and to have my personal information kept confidential **ADD (except where I or my representative appoint someone to have access.)**

Your final say

Providers are currently required to act in accordance with the Charters and to give consumers information about their rights and responsibilities. This includes:

- informing consumers about their rights before they enter care, and
- assisting consumers to understand this information.

It may also include:

- displaying the Charter in the aged care service, and
- including the Charter in the consumer's care agreement.

19 How else could consumers be made aware of their rights under a single Charter?

When we consider the revelations about the way the system and its regulators are failing vulnerable consumers then it is essential that the resident, the family (especially if not local) or, if there is no family, some outside responsible person have the right to appoint a local person or organisation with the necessary powers to oversee the care provided. We anticipate that in many instances such a person or organisation is likely to be associated with and informed by an empowered visitor.

The important lesson from Oakden is that residents and their families do not have anyone readily available to turn to. The most important and essential reform needed in the sector is an empowered community visitors scheme frequently in contact with residents, families (whether local or distant) and the wider community. The sector does not utilise the considerable skills and resources (including medical, nursing and paramedical) in each community to provide support, advice and when needed oversight and supervision of the sector.

Residents and families need assistance and advice when there are problems whether they are aware of them or not. Having someone they already know, who is local and visits them regularly, provide some oversight and able to step in on their behalf is critical when we consider the perverse pressures in the current system and the adverse consequences they have had.

20 Do you have any other comments?

The responses to the many inquiries over the years has been a set of process that did not address the real problems. They can be seen as impression management rather than real reform. The problem that has been repeatedly addressed is adverse publicity and not the fundamental problems in the sector. It has been an exercise in impression management.

The changes made have been tokens that placate the public and reinforce industry's belief in itself. Politicians have been only too ready to accept these tokens themselves and proclaim them publicly. The changes too readily become a token that substitutes for the altruistic service that is not there and the challenging reform that is needed. The proposed Aged Care Quality and Safety Commission is a good example of this. The concern is that this is what is happening here.

We have a Royal Commission which will hopefully advise a major shift in policy and changes that might be reflected in the Charter. It seems an inopportune time to continue with this and other reforms when Government have announced a Royal Commission into Safety and Quality of Aged Care that will undoubtedly be reviewing the regulatory framework and policies supporting it. It will be making it's recommendations in relation to both. The Draft Charter of Aged Care Rights should be put on hold until the completion of all other inquiries including the Royal Commission into Safety and Quality of Aged Care.

A Charter of Rights needs to be there but it is of little interest to the average residents and their families - until it is needed. Trustworthiness is as, if not more, important and that is not being addressed. A Charter like this needs to be legally written, comprehensive and validated by experienced lawyers. It should readily lead into a process that the consumer can activate and use.

These are vulnerable people and their families have limited knowledge and capacity. The care being given needs to have the sort of oversight that enables breaches of their rights to be identified and then informs them of this and guides them as they respond.

We have a system where, as revealed by the abolition of probity requirements in 1997, trustworthiness is not a consideration. It throws out a welcoming mat to all comers including those whose reason for providing care is its potential profitability rather than the altruism, empathy, community values and sense of responsibility that should characterise a sector like this.

Neither the current nor the proposed regulatory system provides a mechanism for ensuring that problems are identified early and are promptly and adequately addressed. Nor do they provide a means whereby remediation can be legally enforced.

Aged Care Crisis and our Legal Issues Columnist Rodney Lewis (practicing Solicitor from ElderLaw) are pressing for an arbitration system to provide a pathway for enforcement, remedying grievances, and recompense when this is required. Such a system could be accessed through the empowered visitors scheme and be supported by the courts.

Aged Care Crisis will be pressing the Royal Commission into aged care to advise regulatory reform that embraces the principles of distributive justice and on site local social control of unacceptable conduct and aberrant cultures. It will include both an empowered Visitors scheme and an arbitration process to address issues promptly and expeditiously.

The evidence clearly shows that the current regulatory system is incapable of addressing the issues and has little impact on the aberrant cultures that plague the sector. We can see no other way of effectively addressing the problems and expect to be able to convince the Royal Commission of this.

Accessibility: It would be helpful for these types of consultations to providing alternative ways to receiving contributions other than online. They could provide a readily available and downloadable Word document with all survey questions. Many people, especially those in aged care, are unable to help themselves and some do not even have computer access. Their vulnerability may also preclude them from being active participants. Those who cannot participate will be among those most directly impacted by the outcomes of these consultations.