Australian Government
Australian Institute of Family Studies

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Department of Health

Draft Charter of Aged Care Rights

Submission from the Australian Institute of Family Studies

Contents

Introduction

The Australian Institute of Family Studies (the 'Institute') aims to contribute to an understanding of issues affecting families by conducting research and communicating findings to policy makers, service providers and the broader community. In particular, the abuse of older people is a key research area for the Institute. In 2016, we engaged in research to scope the evidence base regarding the abuse of older people and are currently completing preparatory work for a national elder abuse prevalence study.[1] In this submission, we respond to the Consultation Paper on the proposed Draft Charter of Aged Care Rights ('Draft Charter') by providing general comments on the Draft Charter, having regard to our research and interest in this area.

Article 14 of the United Nations Principles for Older Persons (1991) provides that:

> Older persons should be able to enjoy human rights and fundamental freedoms when residing in any shelter, care or treatment facility, including full respect for their dignity, beliefs, needs and privacy and for the right to make decisions about their care and the quality of their lives.[2]

In recent years, public interest has grown in relation to the quality of care provided in the aged care system and the protection of older people from all forms of mistreatment, abuse and neglect.[3] Such issues emphasise the importance of having an aged care system that accommodates the protection of care recipients' rights, particularly given their potentially vulnerable position in relation to their caregivers and service providers.[4] To this end, in 2012, the Australian Human Rights Commission emphasised the need for a human rights-focused approach in implementing, monitoring and reviewing aged care reform and identified a charter of human rights as integral to protect and promote the rights and freedoms of aged care recipients.[5]

Under s 54-1 of the *Aged Care Act (1997)* (Cth) (the 'Act'), service providers have an obligation to provide care and services of a quality that is consistent with the *User Rights Principles 2014*. The *User Rights Principles 2014* are made pursuant to s 96-1 of the Act and include the current charters of care recipients' rights and responsibilities.[6] At present, there are separate charters for residential aged care, home care and short-term restorative care:

- Schedule 1 contains the Charter of care recipients' rights and responsibilities – residential care ('Residential Care Charter')
- Schedule 2 contains the Charter of care recipients' rights and responsibilities – home care ('Home Care Charter')
- Schedule 3 contains the Charter of care recipients' rights and responsibilities – short-term restorative care (Part 1, residential care and Part 2, home care).[7]

The discussion in this submission considers the impact of a single Charter of Aged Care Rights and compares the Draft Charter with the existing charters of rights and responsibilities.

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1 Australian Institute of Family Studies (2017); Kaspiew, Carson, & Rhoades (2016a); Kaspiew, Carson, & Rhodes (2016b).
2 United Nations Principles for Older Persons (1991).
3 See e.g. Australian Law Reform Commission (2017); Prime Minister of Australia (2018).
4 See e.g. Kaspiew, Carson, & Rhoades (2016a).
5 Australian Human Rights Commission (2012), p. 24.
6 User Rights Principles 2014 (Cth), Schedules 1–3.
7 This Charter will not be considered in the submission as it contains similar provisions to the Residential Care Charter and Home Care Charter.

It is generally observed that the content of the Draft Charter has been reduced and the language used in the Draft Charter is broader in scope than the existing charters. This suggests the need for further explanatory information to assist individuals and organisations to interpret the Draft Charter and to comply with these rights in practice.

Comments on the Draft Charter

A single Charter of Aged Care Rights

The proposed Draft Charter seeks to compress the existing charters into a single instrument. As with the new Aged Care Quality Standards ('the Standards'),[8] there may be potential for a single, unified instrument to reduce duplication and confusion for care recipients, their families and service providers.[9] As acknowledged in the Consultation Paper for the Draft Charter, it is not clear why some rights articulated in any one of the existing charters are not included in the others. For instance, the Home Care Charter is more detailed than the Residential Care Charter and contains provisions relating to budgeting, fees and communication, absent in the latter. In this respect, there appears considerable benefit in having a unified framework of human rights that applies regardless of the specific nature of aged care.[10]

However, adopting a single instrument over separate charters may also result in a reduction in content and a lack of specificity in addressing the various distinct contexts of aged care. For example, s 1(g) of the Residential Care Charter specifies a right of care recipients to 'live in a safe, secure and homelike environment' while in residential care and 'to move freely both within and outside the residential care service without undue restriction'.[11] This right is particularly relevant in the context of residential aged care as the inappropriate use of physical restraints and/or excessive medication by aged care providers have been described by the Australian Human Rights Commission as 'significant human rights concerns'.[12] It is not clear whether the Draft Charter specifically guards against the use of such restrictive practices. Although this right may be argued to be subsumed by the more general right of care recipients' to 'maintain [their] independence' (provision (d)) in the Draft Charter; the Draft Charter does not provide for explicit and specific articulation of this right. Similarly, the right to 'freedom of speech'[13] is not explicitly articulated in the Draft Charter.

The use of broad language

It is noted that the language used in the Draft Charter appears simpler in its phrasing and broader in scope than the existing charters. Adopting a plain language approach has the potential to reduce complexity, although there is also the potential that the corresponding lack of detail in the Draft Charter's provisions may make it difficult for people reading the Draft Charter to interpret the provisions without further clarification. For instance, the preamble to the Draft Charter states that aged care providers may have to 'balance competing rights' and

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8 Aged Care Legislation Amendment (Single Quality Framework) Principles 2018, Schedule 2 ('Standards'). The Aged Care (Single Quality Framework) Reform Bill 2018 was assented to on 21 September 2018.
9 Department of Health (2018).
10 Nonetheless, it is noted that a limitation of this framework is that the Draft Charter will apply to Commonwealth-subsidised aged care only, as is the case with the existing charters.
11 Residential Care Charter, s 1(g).
12 See Carnell & Paterson (2017), p. 45.
13 Residential Care Charter, s 1(k), Home Care Charter, s 1(1)(e).

will 'resolve these issues sensitively through Consultation and with the spirit of the Charter in mind'. The operationalisation of this clause is unclear on the face of the Draft Charter.

As another example of the use of broad language in the Draft Charter, provision (a) reads: I have the right to '**receive safe and high quality care and services**'. This can be contrasted with section 1(3) of the Home Care Charter, which provides for, amongst other requirements, 'reliable, coordinated, safe, quality care and services which are appropriate to meeting his or her goals and assessed needs' and for the care recipient to be provided a written plan of care and services before, or within 14 days after, they commence receiving care.[14] The existing charters contain consistent references to care 'appropriate to his or her needs'[15] and to care and services 'that best meet his or her goals and assessed needs and preferences'.[16]

The language in the Draft Charter also contrasts with Standard 2 (regarding ongoing assessment and planning with consumers) of the Standards, which emphasises a focus on 'the consumer's needs, goals and preferences'. Consideration may therefore be given to whether the right should receive further articulation, including whether a phrase should be included in this provision to expressly recognise that each recipient's care should be tailored to their circumstances and needs.

In relation to the right to '**maintain control over, and continue to make decisions about my care and personal and social life**' (provision (g)), we note the broader language is proposed to replace a range of provisions in the existing charters about the right to make decisions about various aspects of the care recipient's life, including relationships, friendships, activities, associations of choice, cultural and religious practices, living arrangements, and acceptance of risk and personal responsibility.[17] Although these issues may be covered by the use of the terms 'care', 'personal' and 'social' life, protection for decisions about 'financial affairs and possessions'[18] may potentially be interpreted as excluded by provision (g).

The Draft Charter also reduces the detail in provision (j) by referring to the right to '**complain, and to have my complaints dealt with fairly and promptly**'. This may be contrasted with the current charters (the Residential Care Charter refers to the right to have 'access to advocates' and the right to 'take action to resolve disputes',[19] while the Home Care Charter s (1)(6)(c) also refers to complaints being dealt with 'confidentially'). It can also be contrasted with the new Standard 6, which provides for an organisation to demonstrate that 'consumers are made aware of and have access to advocates, language services and other methods for raising and resolving complaints' as well as processes of open disclosure and review of complaints.

Further, the Draft Charter states that consumers have the right to '**exercise my rights without it adversely affecting the way I am treated'** (provision (k)). On the other hand, the Residential Care Charter specifically refers to the right of care recipients 'to be free from reprisal, or a well-founded fear of reprisal, in any form for taking action to enforce his or her rights'.[20] It is important to consider the potential implications of this proposed change having

[14] In an example of further detail, the Australian Charter of Healthcare Rights refers to safe and high quality care "provided with professional care, skill and competence". It is also noted that the provisions for ongoing review and assessment have been moved to the Standards: see Standard 2.
[15] Residential Care Charter s 1(b).
[16] Home Care Charter s 1(2)(b).
[17] Residential Care Charter, s 1(i)–(q), Home Care Charter, s 1(2)(c) and s 1(2)(e), which refer broadly to 'decisions that affect him or her'.
[18] Residential Care Charter s 1(n).
[19] Residential Care Charter s 1(s)-()–(t).
[20] Section 1(u), see also Home Care Charter, s 1(6)(b) that refers to 'complain … without fear of losing the care or being disadvantaged in any other way'.

regard to the finding in the 2017 Review of National Aged Care Quality Regulatory Processes ('Carnell-Paterson Review') that a fear of reprisal was a significant reason why many people did not make complaints about the quality of care received.[21] It is also suggested that consideration be given to the potential to clarify this provision's wording to cover those instances complaints made under the Draft Charter and rights under law more generally, given that the existing charters explicitly refer to the right 'to full and effective use of his or her personal, civil, legal and consumer rights'.[22]

In addition to the provisions mentioned above, the right to '**choose to have another person speak on my behalf**' (provision (i)) lacks the specificity of section 1(2)(e) of the Home Care Charter and it is unclear whether such a 'person' is required to be someone who is considered to be a representative of a care recipient under the Act.[23]

Limited explanatory information

There is presently limited explanatory information accompanying the Draft Charter, although we acknowledge that materials that can support an understanding of the Draft Charter are currently in development.[24] The provision of explanatory materials will support care recipients to understand their rights, service providers to understand their obligations and to uphold these rights consistently in practice, and parties to identify when these rights have been infringed.[25] For instance, the right to '**be listened to and understood**' (provision (h)) could be accompanied with more specific guidance on how this right could be upheld by organisations and individuals in their delivery of care and services.

Consideration may also be given to whether there is benefit in such guidance being incorporated into the legislative framework rather than existing as an accompanying document or best practice guidelines, in order to clarify the extent of the service provider's legal obligations and establish minimum standards of practice.

There is also the potential for the Draft Charter to be integrated with the new Standards (in particular, the organisation requirements for each standard) to provide some guidance in how providers should act consistently with their obligations under the Draft Charter. For example, the right to 'safe and high quality care' in provision (a), discussed above, can encompass the need for ongoing review and assessment of the care and services provided to the consumer,[26] while the right to 'be informed' about care (provision (f)) can encompass the requirement of the organisation to document a 'care and services plan which is readily available to the consumer' (per Standard 2(3)(d) of the Standards).

The need for definitions

As in the existing charters, the Draft Charters provides for the right to '**live free from abuse and neglect**'. The Carnell-Paterson Review found that the current regulatory environment

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21 Carnell & Paterson (2017), p. 150.

22 Residential Care Charter, s (1)(a); see also Home Care Charter, s 1(1)(e) and the reference to 'human rights' and 'freedom of speech'.

23 Quality of Care Principles 2014 (Cth) s 5 that define a representative of a care recipient as a person 'nominated by the care recipient as a person to be told about matters affecting the care recipient; or a person who nominates himself or herself as a person to be told about matters affecting a care recipient; and who the relevant approved provider is satisfied has a connection with the care recipient and is concerned for the safety, health and wellbeing of the care recipient.

24 Department of Health (2018).

25 See e.g. Australian Commission on Safety and Quality in Healthcare (2012) *Roles in realising the Australian Charter of Healthcare Rights*, which provides guidelines for patient/consumer, health care provider and health service organisations.

26 Standard 2(3)(e). See also e.g. Standard 5 regarding the organisation's service environment and Standard 7 regarding human resources.

(including accreditation, mandatory reporting, quality standards and quality indicators) does not adequately protect residents from abuse and neglect and notes recommendations to enhance the transparency and accountability of the aged care system in its response to abuse and neglect.[27] Due to the significance of this provision, it may be beneficial to have a definition that clarifies what is meant by abuse and neglect noting that there often are differing views on which incidents and behaviour should be captured by those terms. For example, the Australian Law Reform Commission recently proposed a broad understanding of mistreatment, abuse and neglect in relation to the types of incidents that should fall under mandatory reporting, compared with the current definition of 'reportable assault' in the Aged Care Act.[28]

In relation to this provision, we also note that references to living without 'discrimination', 'exploitation', 'victimisation' and 'harassment' in the previous charters are no longer present in the Draft Charter.[29] Consideration may be given to whether these behaviours and others should be included and articulated in the behaviour from which individuals have a right to be protected under the Draft Charter.

Consideration may also be given to the provision of a definition for the term 'consumer' and to the employment of this term in the Draft Charter in place of the term 'care recipient' employed in the existing charters.[30] While we acknowledge the potential for a consumer-directed approach in giving service users more information, choice and control,[31] there is a potential for the replacement of the term 'care recipient' with the term 'consumer' to be perceived as signalling a narrowing of the scope of caring responsibilities by service providers. For example, there may be unique power dynamics and vulnerabilities that exist in this context, where the 'consumer' is often in a vulnerable position and dependent on the organisation providing care, which may be better accommodated by the term 'care recipient'. On the other hand, the use of the term 'consumer' may suggest a broadening of the coverage of the rights from the older person as the care recipient to 'representatives' of the older person.[32] In this context, it is useful to provide a definition of consumer in the Draft Charter to facilitate a better understanding of the coverage of the Draft Charter.

Accessibility of the Charter and complaints mechanisms

The Carnell-Paterson Review raised concerns about the accessibility of information and resources about current complaints mechanisms and the lack of awareness among the community of these safeguards. The Draft Charter specifies that consumers have the right to: '**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**' (provision (f)).[33] Section 1(6)(a) of the existing Home Care Charter currently refers to the right to be 'given information on how to make comments and complaints', which is not explicitly mentioned in this provision. It is worth considering whether a reference to information about available complaints mechanisms

27 Carnell & Paterson (2017), p. 108.
28 Australian Law Reform Commission (2017).
29 Residential Care Charter, s 1(d) and 1(e); Home Care Charter, s 1(g).
30 It is noted that it is.
31 Department of Health (2017).
32 See the definition of 'consumer' in the new Standards that includes a reference to a representative of the consumer: Aged Care Legislation Amendment (Single Quality Framework) Principles 2018, s 4A.
33 This provision is closely similar in language to s 1(r) of the Residential Care Charter.

and avenues could be included in this provision. The Home Care Charter also expressly referred to the right of the care recipient to be given a copy of the Charter and to be helped to understand any information he or she is given.[34] Relevantly, the importance of accessibility of information was raised in the Consultation Paper, and the development of resources and fact sheets to raise awareness about rights and complaints mechanism (and other measures such as the translation of these resources into multiple languages) would support greater accessibility to this information.

More generally, to support the practical effect of the Draft Charter in facilitating compliance by service providers and relevant individuals, consideration may be given to its being accompanied by an additional complaints and enforcement mechanism that is linked with existing mechanisms and provides varied remedies for individuals affected. It has been observed that a limitation of the current complaints process is its focus on dispute resolution rather than holding organisations and individuals to account for breaches of their human rights obligations or providing individual remedies for those affected by human rights breaches.[35] For instance, at present, individuals are unable to initiate action to enforce their rights under the Charter as opposed to if the rights were incorporated into the resident's agreement or enforceable under common law.[36] Barnett and Hayes (2010) have observed that an effective human rights protection system should allow for a range of legal remedies, ranging from compensation, apologies, dispute resolution and other remedial action.

Although the Act provides for certain sanctions in response to non-compliance by an approved provider of their obligations under the Act in certain conditions (such as Chapter 4 for the responsibilities relating to quality and care and user rights), the sanctions are primarily concerned with the operation and consequences for service providers (such as revoking or suspending approval, restricting subsidies and allocation of places) rather than providing effective remedies for those affected. In this regard, it is noted that neither the existing charters nor the Draft Charter refer to the right to remedies for the individuals affected.

Removal of care recipients' responsibilities

Generally, we note that the Draft Charter removes the reference to care recipients' responsibilities, which may maintain the emphasis on the obligations of the service provider and alleviate the onus on the care recipient to comply with responsibilities, having regard to the particular dynamics of aged care that have been discussed.

Conclusion

The existing charters and the Draft Charter are important steps in promoting and fostering a human rights-focused culture in aged care service provision. In this submission, the Institute has provided general comment on the proposed Draft Charter and reflections on specific rights in the Draft Charter. In summary, we note that the Draft Charter, in its current form, uses broad language, which may impact on the ability of service providers and individuals to understand what these rights entail.

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[34] Home Care Charter, s 1(5)(a) and 1(5)(b). See also the new Standard 1(3)(e).
[35] Lacey (2014); see also Australian Human Rights Commission (2012); International Covenant on Civil and Political Rights, art 2.3.3.
[36] See e.g. Barnett and Hayes (2010), p. 72.

This raises the need for further explanatory information (including definitions of the terms employed in the Draft Charter) that strengthens the legal protection of these rights, clarifies the service provider's legal obligations and assists service providers in complying with these rights in their systems, policies and practices. Further, to ensure the strength and effectiveness of the Charter, there is a need for greater awareness of the rights under the Charter and available complaints mechanisms, as well as appropriate remedies for individuals affected.

A further point of consideration for the Department, once the Draft Charter is implemented, is whether a means of monitoring compliance by service providers and/or measuring the practical impact of the Charter on the systems, policies and practices of aged care providers can be adopted, to consider whether it does, in practice, improve the quality of care and experiences of care recipients.

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