



Julia  
farr  
association

**Submission made by Julia Farr  
Association**

**Draft Health and Community Services Charter  
of Rights**

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The Julia Farr Association makes this submission to the Health and Community Services Complaints Commissioner on the Draft Health and Community Services Charter of Rights.

## **1.0 INTRODUCTION**

The Julia Farr Association and its predecessor organisations have been involved with the disability community and older persons for over 130 years. The Julia Farr Association is an independent, non-government entity based in South Australia that fosters innovation, shares useful information, and promotes policy and practice that support vulnerable people to access the good things in life. We are not a service provider – we deliver research, evaluation and information services that are anchored upon the stories shared by people living with disability and other people in their lives. As such, we feel we are in a good position to offer comment and analysis without vested interest.

The Julia Farr Association supports the Health and Community Services Complaints Commissioner’s introduction of the draft Health and Community Services Charter of Rights (hereinafter referred to as the ‘HCSCC Charter’).

We believe that the establishment of the HCSCC Charter is timely in the current environment. There is increasing demand for services due to changes in Australia’s population and demography. Further, there is national commitment to “ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities”<sup>1</sup> through the ratification of the UN Convention on the Rights of Persons with Disabilities by Australia in July 2008.

## **2.0 REPSONSE TO CONSULTATION QUESTIONS**

***Do you agree that the following rights should be included in the HCSCC Charter?***

### **2.1 ACCESS – Right to access health and community services**

***You have a right to reasonable access to health and community services, including child protection services that meet your identified needs, within the resources available to the service provider.***

The Julia Farr Association agrees that this right should be included as it is very important that people have access to health and community supports that are responsive to their needs. This is supported by the United Nations Convention on the Rights of Persons with Disabilities (hereinafter referred to as the ‘UN Disability Convention’) where it states that “[c]ommunity services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs”<sup>2</sup>.

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<sup>1</sup> United Nations n.d., *Convention on the rights of persons with disabilities and optional protocol*, p. 4, <<http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>>.

<sup>2</sup> Ibid, p. 14.

However, we believe the use of the term ‘reasonable’ and reference to providing supports ‘within the resources available to the service provider’ in the description, can set a context of restriction to services. In this way, this wording, however unintentionally, can reduce opportunities for people to access the supports they need.

Mindful of the context provided by the UN Disability Convention, and the obligations this places on Australian governments, our view is that the phrase ‘within the resources available to the service provider’ should be removed from the draft statement. Otherwise the statement places the person’s rights in the context of what a particular service provider is capable of providing instead of the rights-based context of the UN Disability Convention.

We note that the Australian Charter of Healthcare Rights does not make reference to the capacity of service providers to meet the needs of individuals. Instead, stating that an individual has the right to health care and “can access services to address my healthcare needs”<sup>3</sup>.

### Recommendation 1

*The Julia Farr Association recommends that the term ‘reasonable’ and statement ‘within the resources available to the service provider’ be removed from the ‘Access’ right description, to reinforce to people and service providers that the focus of this right should be upheld according to the UN Convention on the Rights of Person with Disabilities and equivalent conventions, and not according to the capacity of the service provider.*

## **2.2 SAFETY – Right to be safe and free from abuse**

***You have a right to be safe from abuse, or the risk of abuse, and to have your legal and human rights respected and upheld. You have a right to receive services free from discrimination and harassment.***

The Julia Farr Association agrees that this right should be included as it is very important that the safety of people who receive health and community supports is protected and promoted. The importance of this is highlighted in Article 16 of the UN Disability Convention.

“State parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside of their home, from all forms of exploitation, violence and abuse, including their gender-based aspects”<sup>4</sup>.

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<sup>3</sup> Australian Commission on Safety and Quality in Healthcare, ‘Australian charter of healthcare rights’, <[http://www.health.gov.au/internet/safety/publishing.nsf/Content/com-pubs\\_ACHR-pdf-01-con/\\$File/17537-charter.pdf](http://www.health.gov.au/internet/safety/publishing.nsf/Content/com-pubs_ACHR-pdf-01-con/$File/17537-charter.pdf)>.

<sup>4</sup> United Nations n.d., *Convention on the rights of persons with disabilities and optional protocol*, p. 12, <<http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>>.

In addition, we suggest that examples of ‘discrimination’ and ‘harassment’ be offered so that consumers are clear about what might constitute discrimination and harassment, and do not filter out areas of potential concern for fear they are being ‘silly’ or a ‘nuisance’.

### Recommendation 2

*The Julia Farr Association recommends that the ‘Safety’ right description include examples of ‘discrimination’ and ‘harassment’, to increase the awareness of people and service providers about what might constitute ‘discrimination’ and ‘harassment’.*

## **2.3 QUALITY – Right to quality service**

***You have a right to have services provided with care and skill. Services should minimise your potential for harm and promote your quality of life. Services received should comply with legal, professional, ethical and other relevant standards.***

The Julia Farr Association agrees that this right should be included in the HCSCC Charter. The UN Disability Convention highlights the importance of people receiving quality supports on an equal basis as others that are also responsive to their needs<sup>5</sup>.

However, in the above draft description, we believe that reference to ‘Services received should comply with legal, professional, ethical and other relevant standards’ needs to specifically reference the UN Disability Convention and the UN Universal Declaration of Human Rights. This will reinforce the importance of ensuring the fundamental rights of people living with disability are acknowledged, protected and promoted when providing supports.

### Recommendation 3

*The Julia Farr Association recommends that specific reference to services complying with the UN Convention on the Rights of Persons with Disabilities and the UN Universal Declaration of Human Rights be included in the ‘Quality’ right description, to reinforce to people and service providers that people’s fundamental rights should underpin how supports are provided.*

We also query the reference to the term ‘minimise your potential for harm’ when referring to the provision of service. As it stands, this phrase could be interpreted as the primary consideration for service delivery and could unintentionally reinforce a sector culture of restrictive practices in the name of safety. In this way, the statement, however unintentionally, reduces the horizon of what is possible in people’s lives. Instead, beginning with ‘quality of life’ as context, and by introducing the concept of safeguarding, this may help sharpen the intent of this draft statement. *Safeguarding* is person-focused and demands careful attention to rights-based

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<sup>5</sup> United Nations n.d., *Convention on the rights of persons with disabilities and optional protocol*, <<http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>>.

lifestyle goals such as choice and citizenship and the health/community support that someone with heightened vulnerability might need to succeed in this.

#### Recommendation 4

We suggest the following rewording of the 'Quality' right description:

*You have a right to have services provided with care and skill. Services should promote your quality of life (in line with articles of the UN Convention on the Rights of Persons with Disabilities, the UN Universal Declaration of Human Rights, and other relevant conventions), and with careful regard for safeguards where these are needed to help ensure you are successfully supported in a way that is responsive to your life choices, and upholding of an ordinary valued life. Services received should comply with legal, professional, ethical and other relevant standards*

#### **2.4 RESPECT – Right to be treated with respect**

***You have a right to have your dignity respected and be treated with courtesy. You have a right to receive services that are respectful of your culture, needs, values and beliefs.***

The Julia Farr Association agrees that this right should be included as people have the right to receive supports that respect their personal needs, experiences and circumstances. The importance of people being treated with respect is one of the general principles of the UN Disability Convention:

“Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices and independence of persons”<sup>6</sup>.

#### **2.5 INFORMATION – Right to be informed**

***You have a right to be provided with relevant information in a way that you can understand. When needed and reasonably practical, you have the right to a competent interpreter.***

The Julia Farr Association agrees that this right should be included in the HCSCC Charter as it is a fundamental right that people living with disability have equal access to relevant information to enable full participation in all aspects of life<sup>5</sup>.

However, we believe the use of the term 'reasonably practical' in the description could prove unhelpful, as it becomes open to interpretation based on an agency's perception of its resource limitations. In this way, this wording, however unintentionally, might reduce the opportunities for people to have equal access to the information they need to make decisions, and be informed about the supports they receive.

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<sup>6</sup> United Nations n.d., *Convention on the rights of persons with disabilities and optional protocol*, p. 5, <<http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>>.

In consequence, our view is that the phrase 'reasonably practical' should be removed from the draft statement. Otherwise the statement places the person's rights in the context of what a particular service provider is capable of providing instead of the context of the UN Disability Convention.

We note that the Australian Charter of Healthcare Rights does not make reference to the capacity of services to provide a competent interpreter. Instead, stating that an individual has a right to "receive open, timely and appropriate communication about my health care in a way I can understand"<sup>3</sup>.

### Recommendation 5

*The Julia Farr Association recommends that the term 'reasonably practical' be removed from the 'Information' right description, to reinforce to people and service providers that the focus of this right is on the individual and not the capacity of the service provider.*

## **2.6 PARTICIPATION – Right to actively participate**

***You have a right to be involved in decisions and choices about the services you receive. You have a right to obtain support and advocacy so you can participate. You have a right to seek advice or information from other sources. You have a right to grant, withhold or withdraw consent at anytime.***

The Julia Farr Association agrees that this right should be included, as the importance of people having the right to make their own decisions is strongly supported by the UN Disability Convention.

We believe the use of the term 'right to be involved', however unintentionally, can reduce opportunities for people to actively participate because it might be taken by service agencies to justify a range of tokenistic practices where the person is not authentically a central player in the decision-making process. Being involved does not guarantee an individual is able to "participate effectively in decisions about his or her health, well-being and welfare" (*Health and Community Services Complaints Act 2004*, section 22<sup>7</sup>).

We further note the tendency for health and community service systems to focus on absolutes in respect of decision-making capacity. In terms of decision-making this presents at least two problems.

First, there is the scenario where a vulnerable person has decision-making authority in her/his life, and where this at times might result in supporters such as family, trusted friends etc being omitted from the decision-making process (or the 'decision-consideration' process, which covers the research, thinking and dialogue that might occur prior to the moment of decision-making) even though the vulnerable person

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<sup>7</sup> Health & Community Services Complaints Act 2004 - Section 22 Content of Charter of Health & Community Services Rights, <[http://www.hcsc.sa.gov.au/documents/02\\_what%27s%20new/h\\_Section-22-Charter-principles.pdf](http://www.hcsc.sa.gov.au/documents/02_what%27s%20new/h_Section-22-Charter-principles.pdf)>.

might have wished for them to be there but wasn't able to express that view in a way that the health/community services could hear.

Second, there is the scenario where a person no longer has decision-making authority in her/his life because a substitute decision-maker has been formally installed, and where this at times might result in the person's wishes, and participation in the decision-consideration process, being disregarded because of this formal arrangement.

### Recommendation 6

*The Julia Farr Association recommends that the term 'right to be involved' be replaced with the term 'right to participate effectively' in the 'Participation' right description, to reinforce to people and service providers that people need to actively participate, and have choice and control, about the supports they receive.*

## **2.6 PRIVACY – Right to privacy and confidentiality**

***You have a right to have your privacy respected and your personal information kept confidential and secure. Personal information about you may not be disclosed without your consent, unless the disclosure is allowed by law. You have a right to request and gain access to your records, unless there is legal restriction in place. You can nominate another person/s with whom information can be shared.***

The Julia Farr Association agrees that this right should be included in the HCSCC Charter. It is a fundamental right that a person's privacy be respect as highlighted in Article 22 of the UN Disability Convention:

"State parties shall protect the privacy of personal, health and rehabilitation information of persons with disabilities on an equal basis with others"<sup>8</sup>.

## **2.7 COMMENT – Right to comment and/or complain**

***You have a right to be listened to and to comment on, or make a complaint about the services provided to you. You have a right to have your complaint dealt with promptly and without retribution as a result of having made a complaint. You have a right to have a representative to support and advocate for you when making a complaint.***

The Julia Farr Association supports the inclusion of this right in the HCSCC Charter as people have the right to be supported to speak up without fear of retribution. This is reinforced in Article 21 of the UN Disability Convention which highlights that:

"State Parties shall take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others"<sup>9</sup>.

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<sup>8</sup> United Nations n.d., *Convention on the rights of persons with disabilities and optional protocol*, p. 15, <<http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>>.

We draw the Health and Community Services Complaints Commissioner to the proceedings of the Julia Farr Association 2007 Loop Conference, which explored the question ‘Why is it so hard to speak up and be heard?’ In supporting the exercise of this right, the Health and Community Services Complaints Commissioner may wish to consider the reported barriers and subsequent recommendations from the Loop 2007.

Key issues included:

- Lack of confidence;
- No information about where to go and how to give my view;
- Too tired;
- Fear of retribution;
- Diminishment;
- Attitudes and behaviour of people running the system;
- Unhelpful processes;
- No collective voice;
- No focus on solutions.

Our subsequent recommendations in support of people giving voice to their rights and concerns were:

- Keep it simple;
- Build the right relationship;
- Focus on supporting people’s strengths and capacities;
- Taking accountable action on people’s needs and concerns.

### **3.0 CONCLUSION**

The Julia Farr Association thanks the Health and Community Services Complaints Commissioner for the opportunity to submit its ideas about the draft Health and Community Services Charter of Rights, and congratulates the Health and Community Services Complaints Commissioner on this important initiative.

The Julia Farr Association hopes that its comments and recommendations are helpful, and welcomes the opportunity to work with the Health and Community Services Complaints Commissioner on the matters raised in this submission, and other issues relevant to establishing the Health and Community Services Charter of Rights.

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<sup>9</sup> United Nations n.d., *Convention on the rights of persons with disabilities and optional protocol*, p. 14, <<http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>>.



We look forward to a successful collaboration.

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