



**Further comment made by
Julia Farr Association**

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

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HCSCC Charter
Further Comment from Julia Farr Association

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INTRODUCTION

The Julia Farr Association welcomes the opportunity to provide further comment on the value of the Health and Community Services Charter of Rights (herein after referred to as HCSCC Charter) under consideration in the South Australian Parliament during the week of June 6th 2011.

The Julia Farr Association and its predecessor organisations have been involved with the disability community 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 people living with disability to access the good things in life. We are not a service provider – we deliver research, consultation, evaluation and information services that are anchored upon the stories shared by people living with disability, family members and other supporters. As such, we feel we are in a good position to offer comment and analysis about the value to the disability community of the Health and Community Services Charter of Rights.

The Julia Farr Association strongly supports the HCSCC Charter. Drawing on our work, we have endeavoured in the present document to answer the three questions posed by the HCSCC.

COMMENTS

Why did you express your interest in becoming an HCSCC Charter Champion?

Our experience has told us that, for too long, people living with disability been passive recipients of health and community services with little choice or control in what is done to them^{1 2 3} In line with progress toward social inclusion and active citizenship, the HCSCC Charter provides a framework of clearly defined rights for people living with disability as health and community service consumers.

Identifying policies and practices which can support and protect the rights of people living with disability is at the heart of the Julia Farr Association's mission. Our work is anchored on two principal values: that people have authentic *personal authority* in their lives, and that people are active citizens in community life (termed *active citizenship*).

People living with disability can experience increased vulnerability and can enter, and become trapped in, cycles of disadvantage when they are unable to access the supports they need, maintain personal authority in their lives, and actively participate within their community. Mindful of these circumstances, the Julia Farr Association believes the most important contextual point we can make is that people living with disability are citizens first and foremost, and as such should be afforded the same rights as other people enjoy in relation to health and community services⁴. The Social Inclusion Board (2010)⁴ locates the strengthening of dignity, rights and protection as a key element of activating citizenship for people living with disability. The HCSCC Charter of rights will play an important role in ensuring that people have genuine opportunities to have and retain choice and control in their lives and are supported in ways that assert and uphold their rights and status as valued citizens.

In society, deeply felt values are typically codified into statements of rights. While the rights of people living with disabilities have been codified via other sources, principally the UN Convention on the Rights of Persons with Disabilities (2006) and ratified by Australia in

¹ National People with Disabilities and Carer Council, (2009) SHUT OUT: The Experience of People with Disabilities and Their Family in Australia accessed May 24 2011: http://www.fahcsia.gov.au/sa/disability/pubs/policy/community_consult/Pages/default.aspx

² People with Disability Australia Incorporated (2009) submission: National Human Rights Consultation. accessed May 20, 20 11: <http://www.pwd.org.au/systemic/abuse.html>

³ Social Inclusion Board 2010, *Activating citizenship. A social inclusion approach for disability in South Australia*, Government of South Australia, Adelaide.

⁴ Social Inclusion Board 2010, *Activating citizenship. A social inclusion approach for disability in South Australia*, Government of South Australia, Adelaide.

2008, this does not mean that such rights are routinely advanced and upheld in the everyday lives of people living with disability⁵

Commenting on the impotence of treaties such as the UN Convention on the Rights of Persons with Disabilities in a submission to the National Human Rights Consultation, People With Disabilities Australia Inc. (PWD, 2009 p.11) states that “it is now generally accepted that these treaties have done little in practice to protect, promote and fulfil the rights of persons with disability.”⁶

People With Disabilities Australia Inc. (2011 p.11) goes on to suggest that in part this is because such treaties “both in the formulation and in their implementation have not penetrated to many of the specific forms of human rights violation that persons with disability experience.”⁷

While people living with disability are said to have the same fundamental rights and responsibilities as other members of the community, there is strong evidence to indicate that people living with disability are overrepresented as victims of crime, violence, fraud and sexual assault. They are also more likely to experience multiple episodes of all forms of abuse and neglect.⁸

While the Disability Discrimination Act 1992 provides some protection from discrimination and harassment for people living with disability in areas of employment, education and the provision of goods and services, many people living with disability remain significantly disadvantaged in Australian society with regard to key indicators of social and economic wellbeing⁹

The Julia Farr Association believes that every opportunity should be taken to advance and uphold the rights of people living with disability, and this includes specific measures in specific context. People living with significant disability can come to rely heavily upon health and community services for assistance with the exercise of personal authority and

⁵ 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>

⁶ *People with Disability Australia Incorporated (2009) Submission: National Human Rights Consultation. accessed May 20, 2011*

⁷ *People with Disability Australia Incorporated (2009) Submission: National Human Rights Consultation. accessed May 20, 2011: <http://www.pwd.org.au/systemic/abuse.html>*

⁸ *French, Dardel and Price-Kelly, (2010). Right's denied: towards a national policy agenda about the abuse, neglect and exploitation of persons with cognitive disability in Australia. Accessed May 27, 2011: http://www.hreoc.gov.au/disability_rights/hr_disab/vhb/index.html*

⁹ *Social Inclusion Board 2010, Activating citizenship. A social inclusion approach for disability in South Australia, Government of South Australia, Adelaide.*

with daily life as valued active citizens in their community. Given the values that are at stake through such assistance, and given the history of vulnerability that people have experienced in services, the Julia Farr Association believes strongly that the HCSCC Charter is an urgent and welcome addition in the current environment.

What do you think the HCSCC Charter means to your group, work unit or agency?

The Julia Farr Association welcomes and strongly endorses a framework of human rights as set out by the HCSCC Charter as a safeguard for people living with disability in relation to health and community services. The HCSCC Charter provides an opportunity for service providers to be more aware of, and accountable for upholding, the rights of people living with disability. It also provides an opportunity for people living with disability to become aware of their rights and gain skills with which to exercise their rights.

Therefore, the Julia Farr Association believes that the HCSCC Charter must be accompanied by effective education strategies with service providers and people living with disability. Further, such education must be provided in consultation with people living with disability.

The Julia Farr Association has identified through extensive consultation with the disability community that people living with disability continue to experience situations where their fundamental rights are not being protected (upheld) or promoted (advanced). These experiences indicate that people living with disability are not yet routinely enjoying the same rights that other South Australian citizens enjoy in relation to health and community services.

Therefore, the Julia Farr Association emphasises the need for safeguards to protect the rights of people living with disability as full citizens. One such safeguard is the HCSCC Charter, together with robust implementation arrangements.

The Julia Farr Association recognises that a power imbalance can exist in the relationship between the service provider and a person living with disability. There are many reasons why a person may not feel able to initiate a complaint about a service. The Julia Farr Association 2007 Loop conference explored with people living with disability the question 'Why is it so hard to speak up and be heard?' The reasons given included lack of confidence, lack of information about where to go and how to give a view, tiredness, fear of retribution, feelings of diminishment, the attitudes and behaviour of people running the system, no collective voice, no focus on solutions and unhelpful processes¹⁰

¹⁰ 2007 loop conference proceedings accessed May 27, 2011: <http://juliafarr.org.au/>

Therefore we cannot solely rely upon a complaints mechanism that is dependent upon the person living with disability actively and personally initiating a complaint.

The likelihood of a person living with disability actively making a complaint is further diminished when other factors apply, such as:

a) The service agency is also the landlord of the property where the person resides

When this happens, the stakes are raised significantly for the person who is not happy about services, because if they complain they bring into uncertainty not only their support arrangements but also the roof over their head¹¹;

b) Impoverished family/personal networks

It is not uncommon for people living with disability, because of circumstances, to be at greater risk of diminished personal networks of family and friends when compared to their non-disabled peer citizens. The relative absence of an active, supportive network of family and friends can contribute to the person's isolation and therefore their vulnerability¹². Dependence on relationships with their professional support providers presents a further barrier to speaking up, because doing so may pose a risk to the few relationships they have. Also the absence of regular visits from, and time with, family and friends, means there is none of the natural 'service monitoring' that takes place through such relationships.

The Julia Farr Association emphasises the need for additional mechanisms to be in place that in effect bring the complaints mechanism to the person without that person having to actively go out and seek it. Article 16 (3)¹³ of the UN Convention on the Rights of Persons with Disability (UNCRPD, 2006) requires that parties "ensure that all facilities and programs designed to serve persons with disabilities are effectively monitored by independent authorities".

What practical difference do you think the HCSCC Charter of rights will make for people who seek or use health and community services in SA?

Understandably, people living with disability express caution about whether the articulation of human rights can make a difference in their lives. Many people living with disability experience comprehensive disempowerment, lack resources and are exposed to retribution and stigma if they attempt to exercise a right. Frequently human rights violations

¹¹ Swift, K 2008, 'Creating home: An exploration of the efforts and commitment to create individual lives, not just bricks and mortar', electronic version, *Crucial Times*, issue 40, pp. 1-2, <<http://www.cru.org.au/crutimes/CT40/CT40.doc>>.

¹² *Supported Accommodation Task Group 2006*, Accommodation and personal support for people with disabilities in South Australia. Consultation paper, Department for Families and Communities, Adelaide, South Australia.

¹³ United Nations n.d., *Convention on the rights of persons with disabilities and optional protocol*, accessed May 27, 2011, p. 12, <<http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>>

experienced by people living with disability are of a systemic or structural nature, with the greatest violations experienced by those least able, or least supported, to speak up¹⁴.

This highlights the important role for advocacy organisation in advancing and upholding the rights of people living with disability, and seeking appropriate remedies where there are issues. Such vehicles for people's voice and personal authority can help ensure that human rights actually penetrate to the lived experience of people with disability, and a device such as the HCSCC can assist the helpful focus of such advocacy endeavours.

Evidence from the UK and New Zealand^{15, 16} indicates that when human rights are formalised people living with disability are afforded greater power to exercise their rights and resolve issues. Also noted was improved accountability and a shift away from inflexible policies toward those which are more accommodating of the circumstances and needs of individuals.

The Julia Farr Association believes that, when accompanied by an effective education strategy plus an independent complaints mechanism plus an independent community visitor mechanism, the HCSCC charter of rights has the potential to provide people living with disability with:

- a human rights framework against which all aspects of service provision can be measured
- greater supports and recourse to exercise their rights and choices
- a better experience of using health and community services
- greater involvement and control as health and community consumers
- a safeguard mechanism for advancing and upholding the rights of people with disability as service consumers
- better informed, more accountable, more respectful service providers
- an opportunity for people living with disability to become more aware of their rights and to develop skills in advancing and upholding those rights.

¹⁴ *People with Disability Australia Incorporated (2009) Submission: National Human Rights Consultation. accessed May 20, 2011:*
<http://www.pwd.org.au/systemic/abuse.html>

¹⁵ *British Institute of Human Rights 2008, The human rights act – Changing lives, Second Edition, accessed 24 May 2011:*
<http://www.bihhr.org.uk/sites/default/files/BIHR%20Changing%20Lives%20FINAL_0.pdf

¹⁶ *Brereton, R 2009 (former NZ Human Rights Commissioner), 'Briefing notes to Julia Farr Association about Submission to the National Human Rights Consultation', 11 June, p. 5, JFA internal document.*

CONCLUSION

The Julia Farr Association thanks the Health and Community Services Complaints Commissioner for the opportunity to comment further in the support of the Health and Community Services Charter of Rights.

The Julia Farr Association hopes that its comments are helpful, and welcomes the opportunity to work with the Health and Community Services Complaints Commissioner on issues relevant to establishing the Health and Community Services Charter of Rights. We look forward to a successful collaboration.

For further information about this submission, please contact:

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PERMISSION

I give permission for HCSCC to publicly release the comments to the three questions accompanied with first name, general title and post code.

I am willing with HCSCC's support to speak with the media about the HCSCC Charter. My contact details are show above.