



Wellbeing through health for all South Australians

Submission in response to the  
Draft Charter of Health &  
Community Services Rights

August 2010

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## **Submission in response to the Draft Health and Community Services Charter of Rights**

**August 2010**

### **EXECUTIVE SUMMARY**

The Health Consumers Alliance (HCA) is the state peak body representing the interests of South Australian health consumers.

HCA welcomes the opportunity to comment on the Draft Health & Community Services Charter of Rights as it considers the Charter a fundamental aspect of the health care system in South Australia. It is imperative that the Charter reflects the needs and experiences of consumers and carers if it is going to make an impact on the safety and quality of health care in South Australia.

Under the Health and Community Services Complaints Act 2004, the Health and Community Services Complaints Commissioner, HCSCC, has to develop a Charter of Health and Community Services Rights (the Charter).

The HCSCC Charter applies to all health consumers and service users and health and community service providers in South Australia, and to the carers and nominees who act on behalf of service users. The HCSCC Charter covers a wide range of service providers, in the public, private or community services sector.

Health consumers and carers have a strong interest in the development of the Charter and view it as essential to the achievement of consumer-centred care.

On 22 July 2008, Australian Health Ministers endorsed the Australian Charter of Healthcare Rights and recommended its use nationwide. The Australian Charter is the national benchmark.

From 1 July 2010 the draft HCSCC Charter was widely distributed for consultation. The HCSCC encouraged and proactively sought participation from consumers and carers, health and community service providers, peak bodies, non-government organisations, professional organisations and government departments.

To ensure as wide as possible engagement of consumers and carers in the development of HCA's response to the draft Charter an engagement plan was developed in line with the International Association of Public Participation (iap2) Spectrum of Engagement.

This report is a summary of the comments and suggestions received from consumers, carers and/or their representatives. HCA, as the peak body, has distilled this feedback from consumers and carers into a set of recommendations for consideration by the HCSCC.

Importantly, there was a general consensus amongst consumers that the SA Charter of Rights not be expressed in such a way that reduces the potency of their Rights as expressed in the Australian Charter. Consumers, therefore, were



very concerned that the content of the SA Charter, and the inclusion of community services, does not diminish or “water down” their Rights as consumers of health services.

Fundamentally, consumers want to be treated as a person, “holistically”, and as a unique individual, and consumers see this “culture of care” as the foundation of safe, quality, consumer-centred care.

*What are my human rights? I read them in the UN covenant of Human Rights.  
I suffer from Depression and I can't even get Life Insurance.*

## RECOMMENDATIONS

In response to the Draft Health & Community Services Charter of Rights, and based on the feedback from HCA members, consumer advocates and stakeholders, HCA is pleased to make the following recommendations for consideration by the Commissioner and the Charter Project Reference Group.

1. That the SA Charter not be expressed in such a way that it diminishes the rights or provides lesser rights for health consumers than the Australian Charter of Healthcare Rights.
2. That the SA Charter adopts the same Guiding Principles as the Australian Charter of Healthcare Rights.
3. That the Charter document provides a clear explanation of the purpose and role of the Guiding Principles.
4. That consideration is given to replacing “you” with “I” as in the Australian Charter or “everyone” in the Rights. For example, “everyone has a right to access health and community services...that meet their identified needs”.
5. That Right number 1, Access read: “I have a right to access health and community services, including child protection services that meet my needs.”
6. That Right number 2, Safety read: “I have a right to safe care and treatment, and to be safe from abuse and harm. I have a right to be informed about any errors or mistakes in my care and to be involved in decisions about how to fix them. I have a right to receive services free from discrimination and harassment that respect and uphold my legal and human rights.”
7. That Right number 3, Quality read: “I have a right to services and evidence-based care provided with professional care, skill and competence. I have a right to services that promote my wellbeing and quality of life.”
8. That Right number 4, Respect read: “I have a right to services that treat me with courtesy and respect my dignity. I have a right to ask, receive and choose services that are respectful of my culture, beliefs, values and personal characteristics.”
9. That Right number 5, Information, be amended to Communication, and read: “I have a right to receive open, clear and timely communication in a way that I can understand and that enables me to make informed decisions about services, treatment, options and costs. I have the right to a competent and professional interpreter.”
10. That Right number 6, Participation read: “I have a right to be involved in decisions and choices about the services I receive and to join in making decisions about the planning of health and community services. I have a right to obtain support and advocacy so I can participate, to seek advice or information from other sources and to have my advocate or carer



participate with me. I have a right to grant, withhold or withdraw consent at anytime.”

11. That Right number 8, Comment read: “I have a right to be listened to and to comment on, or make a complaint, about the services provided to me. I have a right to have my complaint dealt with promptly and without retribution, or fear of retribution, as a result of having made a complaint and to have my concerns addressed. I have a right to have a representative of my choice to support and advocate for me when making a complaint.”
12. That the HCSCC seek appropriate resources to communicate and implement the Charter.
13. That the Health and Complaints Advisory Council monitor and evaluate the implementation of the Charter and its impact.



## **INTRODUCTION**

The Health Consumers Alliance (HCA) is the state peak body representing the interests of South Australian health consumers. The Alliance is the independent voice of health consumers, facilitating and supporting consumer leadership through consumer networks and broad community engagement activities.

HCA is consumer-led, with a Board elected by the membership, responsible for the governance and strategic leadership of the organisation.

Reflecting the consumer perspective, HCA promotes a holistic and integrated approach to health and wellbeing. As a fundamental aspect of health, mental health is a key focus within HCA.

HCA's vision is *"Wellbeing though health for all South Australians"*. We work together with our members, health consumer advocates and stakeholders to provide a respected and informed consumer voice to influence the development of quality health services.

HCA welcomes the opportunity to comment on the Draft Health & Community Services Charter of Rights as it considers the Charter a fundamental aspect of the health care system in South Australia. It is imperative that the Charter reflects the needs and experiences of consumers and carers if it is going to make an impact on the safety and quality of health care in South Australia.

## **THE CHARTER**

Under the Health and Community Services Complaints Act 2004, the Health and Community Services Complaints Commissioner, HCSCC, has to develop a Charter of Health and Community Services Rights (the Charter).

The Charter will set out the rights of people who use health and community services. Once developed, the Charter will be used when a complaint has been lodged to enable HCSCC to determine whether a health or community service provider has acted reasonably.

The HCSCC Charter applies to all service users and health and community service providers in South Australia, and to the carers and nominees who act on behalf of service users. The HCSCC Charter covers a wide range of service providers, in the public, private or community services sector.

The Draft Charter is a brief statement about eight rights which are based on the principles as noted in the Health & Community Services Complaints Act 2004. It is targeted specifically at service users, and explains each of the rights as statements about what this means for the individual. The Charter also includes four guiding principles which are general requirements for all of the rights.



## **RIGHTS AND CONSUMER CENTRED CARE**

Consumer involvement in all levels of health decision-making and community concern for safe, quality healthcare are now established features of the Australian healthcare landscape. The creation of a South Australian Charter of Health and Community Services Rights is a key element that can enable safe, quality healthcare. Consumers have a strong interest in the development of the Charter and view it as essential to the achievement of consumer centred care.

HCA considers the Health and Community Services Complaints Act 2004 to be important and significant legislation that provides a good foundation for the resolution of health complaints and development of a consumer-centred health system.

The introduction of the Act and the establishment of a Commissioner was an important development in improving access to quality health care which is responsive to the needs and concerns of South Australians.

The Act Review, conducted in 2008, recommended that the HCSCC establish a Charter for Health and Community Services Rights as required by the Act and that section 22 of the Act be amended to include an additional Charter principle stating that a person should be entitled to nominate a representative to assist in resolving a complaint. HCA supported this recommendation, emphasising urgency on the basis that a Charter gives voice to the rights of consumers and offers a clear framework for service providers. The Government supported the recommendation.

In 2009 HCA sought high priority attention to the establishment of a Charter and the allocation of resources for development and promotion.

On 22 July 2008, Australian Health Ministers endorsed the Australian Charter of Healthcare Rights and recommended its use nationwide. The Australian Charter is the national benchmark. An important principle for HCA is that the rights of health consumers in South Australia as provided in the Charter of Health and Community Services Rights should not be lesser than those already enshrined in the Australian Charter.

## **HCA CONSUMER ENGAGEMENT**

From 1 July 2010 the draft HCSCC Charter was widely distributed for consultation. A discussion paper was developed that provided background information about the office of the Health and Community Services Complaints Commissioner, the legislative requirements, the application of the HCSCC Charter, and a draft Charter.

The HCSCC encouraged and proactively sought participation from consumers and carers, health and community service providers, peak bodies, non-government organisations, professional organisations and government departments.





HCA has been involved in the process from the outset as a member of the Charter Project Reference Group. To ensure as wide as possible engagement of consumers and carers in the development of HCA's response to the draft Charter an engagement plan was developed in line with the International Association of Public Participation (iap2) Spectrum of Engagement.

The purpose of the HCA Charter engagement process was to:

- design and facilitate a process to inform and consult with various target audiences regarding the HCSCC Charter;
- produce a report on the process to be forwarded to the Complaints Commissioner and the HCSCC Charter Project Reference Group;
- support consumer and community engagement in the development of the HCSCC Charter in line with HCA's Corporate Plan 2010;
- ensure the health consumer voice is heard in the development of the HCSCC Charter;
- engage with HCA's target audience to:
  - inform consumers about the development of the HCSCC Charter.
  - involve consumers in order to ensure that their concerns and aspirations are directly reflected in HCA's Charter response to the Complaints Commissioner and the HCSCC Charter Project Reference Group.
  - provide feedback to consumers on how they have influenced the development of the HCSCC Charter.

The target audiences for HCA's engagement activities included:

- Statewide Clinical Network Consumer Advocates
- Other Consumer Advocates and Representatives
- South Australian CHF Consumer Representatives
- HCA Board members
- HCA Members
- SA Health CACs, CAGs and HACs
- Mental Health Consumers / Carers
- New and Emerging Community Representatives
- Carers SA

The following is a summary of the comments and suggestions received from consumers, carers and/or their representatives as part of the following engagement activities:

- HCA Members Policy Forum held on 8 July 2010;
- Consumer Safety & Quality Forum held on 28 July 2010 attended by consumers advocates from SA Health advisory groups;
- Individual in-depth structured interviews with mental health consumers;



- An online survey advertised in HCA's e-bulletin and open to consumers, carers and service providers (hard copies were provided to individuals upon request);
- Specific feedback from representatives of Carers SA and the South Australian Refugee Health Network (SARHN).



## **CONSUMER FEEDBACK ON THE DRAFT CHARTER**

### **Guiding Principles**

Overall consumers had a strong preference for the three Guiding Principles in the Australian Charter of Healthcare Rights and were unsure of the purpose of the five Guiding Principles in the Draft Charter.

Further, consumers were of the view that the Guiding Principles in the Draft Charter might be more appropriate to help filter and determine what is “reasonable” when the HCSCC has to make a judgement against standards.

Principles should be positive statements not negative ones and focus on why the Charter is important, speak to what it hopes to achieve and provide a context in which to place the rights. That is, the concept that it is “a space for claiming the right to have rights”.

Consumers felt that it is very important to get this right as Australia does not have a rights/complaints culture so a culture shift is required which needs vision and commitment. Currently people may not comment or complain for fear of affecting service access and quality of care.

The Charter will be critical to the creation of a new culture in South Australia. Thus it is essential to ensure that all groups feel enabled to make complaints and that cultural barriers are addressed.

Consumers expressed specific concern about older people, vulnerable groups, mental health consumers, culturally and linguistically diverse consumers, and indigenous consumers. This is of particular importance when there is a clear dependence and ongoing care relationship for a particular consumer or carer.

#### ***1. DIVERSITY***

Some consumers prefer the term embraced rather than supported here, as it is a cause for celebration rather than a problem to be managed.

Diversity means that individuals and groups have unique and complex needs and these must be recognised as fundamental to the achievement of the Rights.

#### ***2. CAPACITY***

Consumers expressed the view that it is important for the structures and processes to be in place to support this Principle. For example, individuals need to be encouraged to set up the legal documents for their care when unwell, such as, Advanced Care Directives. It is important that people are prepared and have made these decisions in advance when they have the capacity to do so.



Further, there are a range of support processes that need to be in place such as timely information, the time to properly consider the information to make informed decisions, and access to independent advocacy.

SARHN have requested that CALD consumers be included.

Consumers and carers felt that this principle should be expressed as a positive statement or not at all, as the power imbalance in the relationship with service providers can be a real and serious issue from the consumer and carer perspective.

### *3. PARTNERSHIP*

Again, consumers considered this Principle from the perspective of the real power differentials that exist and how to make this happen in practice. Individual consumers and service users have little power to insist that service providers work in partnership.

This Principle is at risk of just being a nice “motherhood” statement.

Consumers questioned the use of the term relevant with respect to information? Who decides what is relevant?

### *4. CONTRIBUTION*

Consumers questioned the inclusion of this statement as a Guiding Principle and expressed a view that it may be interpreted by consumers as skewing the Rights in favour of service providers. Consumers and, especially, carers should also be recognised for their contribution to health, wellbeing and welfare. Increasingly health promotion programmes expect consumers to take responsibility for their own health and/or management of their condition. Carers are expected to take on more and more responsibility. Consumers and carers as advocates, peer workers, and advisers, make a huge contribution to the development of safe, quality, consumer centred care.

### *5. AUTHORITY*

Consumers were generally of the view that this should not be included as a separate Principle and is covered by Principle 2, Capacity.

## **My Rights - What This Means**

Generally, consumers preferred the term “Everyone” rather than “You” as it helps set up the inclusive focus of the rights and reinforces the important culture shift.

Importantly, there was a general consensus amongst consumers that the SA Charter of Rights not be expressed in such a way that reduces the potency of their Rights as expressed in the Australian Charter. Consumers, therefore, were very concerned that the content of the SA Charter, and the inclusion of community

services, does not diminish or “water down” their Rights as consumers of health services.

Consumers recommend that the Australian Charter be regarded as the benchmark and only changed if necessary to incorporate the views of users of community services.

SARHN commented that the Rights of refugees have been infringed in the past due to a lack of translator services and inappropriate use of children leading to misdiagnosis, poor treatment compliance and abuse of children.

Fundamentally, consumers want to be treated as a person, ‘holistically’, and as a unique individual, and see this as the foundation of safe, quality, consumer-centred care.

*What are my human rights? I read them in the UN covenant of Human Rights. I suffer from Depression and I can't even get Life Insurance.*

#### 1. ACCESS – Right to access health and community services

Access is clearly a fundamental right as without access the other rights are irrelevant. Consumers see access as *right time, right place, and right service* as this is the standard by which health care should be delivered.

There was considerable concern about the use of the term reasonable as a possible “get out” clause for service providers. Reasonableness is rightly a concern of the HCSCC and the concept will be used by the Commissioner as defined by the Act, and other professional service standards and codes, but is not relevant to a rights statement *per se*.

Generally, consumers preferred the wording of the Australian Charter. Consumers made specific comments in relation to:

*Waiting lists - a right is important, however, if adequate resources are not available for access then this is a frustrating statement.*

*Equitable access - the right to access sounds good, but how does a “stated” right change the issue of “resources” available to service providers?*

*Health services need to consider how they prioritise acute access (bed allocation) for individuals in mental health crisis.*

*Often individuals who are in crises who have insight will be assessed as a low priority for a bed compared to an individual with early psychosis.*

*This right is nice in ‘theory’, it needs to be what consumers deem is important in access not what service providers think is important.*

*Access should be a fundamental right; however, it's not attainable for all.*

Further, consumers expressed concern that regional access is often problematic and generally expressed concern about the phrase “within the resources available to the service provider”.

Equity in terms of access and delivery as well as quality and consistency were common concerns. Therefore, consumers were to an extent unconvinced about this Right as it is currently drafted.

Carers SA commented that the special needs of carers as consumers should be recognised and the changing needs of a situation over time. It needs to be recognised that access for some is dependent on the availability of a support person.

## 2. SAFETY – Right to be safe and free from abuse

Health consumers were generally of the view that this Right, as is, captures and reflects the needs of users of community services only. The statement needs to be enlarged to cover health more effectively. Safety issues are very relevant to health but it is safety from a different but still important perspective.

*In my experience as a carer there wasn't abuse, discrimination or harassment within hospital. However there are 'power' imbalances. The fear that if you 'complain' or rock the boat that service provision can be altered.*

*There is a need where individuals are weak or too ill to have an advocate to uphold these rights.*

*When you are becoming psychotic, you know there will be a point where you are unable to make decisions for yourself and your safety. Knowing that I have been abused whilst unwell and in the care of the Mental Health system, I don't want to access services that have let me down and failed to protect me.*

*When I am in hospital and unwell, I feel I should be safer than when I am in my home in the community. A closed ward should provide this level of safety and care.*

*The biggest thing for me is the need to change closed wards to separate male and female closed wards. Until this happens, I do not believe that the Mental Health Services can minimise my potential for harm or promote my quality of life.*

The wording needs to be inclusive and refer to safe treatment and care, open disclosure, zero harm and the right to 100% safe healthcare.

Carers SA commented that lack of access to care can equate to abuse for carers.

## 3. QUALITY – Right to quality service

Consumers were generally satisfied with the wording of this Right but with the addition of “services to be provided competently and with care and skill”.

*Services need to be delivered to consumers through dignified care. The culture of nursing and care needs to uphold the dignity and rights of the unwell and those receiving care.*

*It would be nice to say 'yes', a right to quality services is important. I don't find that health services are delivered with a lot of care or skill.*

*The focus on GP Super Clinics and delivering the 'best' service: what about people (elderly and frail) who can't get there. They forget about the surrounding issues.*

*If someone is in 'emotional pain' they should be supported with care and through an understanding service.*

Some consumers felt that there should be an emphasis here on evidence based care and information. How can we make informed decisions without evidence based care? This is particular critical for those people who do not ask questions of their health professionals. The Right to quality advice should be included.

SAHRN commented that access and quality are inextricably linked.

Carers SA commented that access to quality care would reduce the burden on carers, and that quality care recognises that support provided to the consumer and their carer are inextricably linked.

#### *4. RESPECT – Right to be treated with respect*

Consumers expressed a preference for the wording in the Australian Charter, specifically the link to needs and respect for difference.

*A holistic view of health is required. When an individual's values/morals are undermined, this can physically set back recovery.*

*The principle of 'do no harm' – when you are disrespected, you are harmed by a professional in a role of power.*

*Dignity respected is the big thing when discussing safety and being free from abuse.*

*Being told that I am "behaving inappropriately" when I am unwell by nursing staff is not respectful.*

*Because I am not talked to, given medication or kept safe from male advances when I request assistance – I have absconded from hospital. In one case, I absconded to my home in order to access PRN medication (prescribed by my Psychiatrist) that I was refused by the nursing staff to relieve my psychosis.*

*Accountability: it's okay to say that I am 'respected'. If I make a complaint, and the conclusion is that I have been disrespected... so what? Without accountability, the right is baseless.*

SAHRN commented that when people are treated respectfully they are more likely to be engaged and self responsible.

## 5. INFORMATION – Right to be informed

Most consumers questioned the change from communication to information as communication implies a two way process and is therefore empowering, whereas information suggests a one way process. Good communication will be inclusive of information anyway.

It was generally thought that the addition of interpreter use here was a plus without the qualifying “when needed” statement.

The onus should be on the provider to argue why they couldn’t meet the standard rather than creating a lower standard in the first place.

Consumers suggested that the right to access an advocate and the rights of carers should be included as well.

*People don't tell you about anything, unless you know something and ask specifically.*

*It's important to receive the information that we ask for without any excuses or without internal processes so that obtaining information is near impossible.*

*If someone is writing something about you, you should have a right to know that information.*

SARHN commented that information is essentially a two way process of communication. Reducing it to one way information is too limiting as giving and receiving is important for effective care

## 6. PARTICIPATION – Right to actively participate

Consumers felt that this could be strengthened by us of the present tense. For example, right to make decisions and choices about your care and treatment.

*An understanding of holistic health is required. My elderly mother was discharged from hospital with Depression, poor oral care, poor pain management and a lack of desire to live.*

*I tell a psychiatrist that I cannot take certain medications because of the paradoxical effect and then am forced to take medication that I have stated makes me unwell.*

*When I have accessed support and advocacy through my family, they are often not listened to by staff or invited to be part of ongoing care planning.*

*I may be too unwell to participate. In this case, I am not asked; I don't have a choice if I am involuntarily detained.*

*What advocacy? What advocacy group can I get help from? What power does any advocacy group have to do anything?*

SAHRN commented that the link between participation and information/communication is important as they are inseparable. Those outside of the health system have little knowledge and really need access to advocacy.



Carers SA commented that carers need recognition of their role as partners in care and their right to participate must be honoured.

#### *7. PRIVACY – Right to privacy and confidentiality*

Consumers support the statement about nominating another person with whom information can be shared.

*Yes. When Dementia and acute Mental Illness or a lack of mental capacity is present, other procedures or considerations need to be in place.*

*Family members have provided staff with information of my symptoms worsening and have not been listened to and have been told to leave the ward.*

*When you try and help someone and the privacy issue comes up, preventing you from providing assistance.*

Consumers had some discussion about mandatory reporting and privacy issues.

SAHRN commented that the need for transparency in system should not be lost by a good principle misused.

Carers SA commented that privacy is used as a barrier to information being shared which can exacerbate the demands on carers further.

#### *8. COMMENT – Right to comment and /or complain*

Consumers support the statement about the right to have your complaint dealt with promptly and without retribution and regard it as an important ground rule. Some consumers expressed a preference for the wording in the Australian Charter.

*It is really important to have this right. Something can happen and you do have the right to say something.*

*Many people do not have the where with all to comment during a crisis and amidst receiving a service. The clarity to complain about problems often does not exist when under emotional stress.*

*The contexts of rights in the midst of illness – people are totally subsumed by illness, intervention, helplessness and worry.*

*It is essential for hospital and community services to have clear complaints procedures otherwise it is completely disempowering for consumers when they need to make a complaint or provide feedback.*

*Often when things go wrong in mental health services, you feel insignificant. You feel as though no-one is listening or cares when you complain.*

*People will advise you when you are well... not to go through it again. Not to complain, not to re-traumatise yourself. Move on.*



SAHRN commented that all consumers should be given a simple form on how to make a complaint, all the time.

Carers SA commented that carers are also unwilling to comment for fear of making a situation worse for themselves and the person they care for, therefore, promotion of rights and advocacy support is essential to overcome this.

## **Other Related Matters**

### *1. IMPLEMENTATION*

Consumers expressed concern about the implementation of the Charter and if sufficient resources will be invested in communication and raising broad community awareness. The following suggestions and ideas were put forward:

- a communication strategy needs to be developed and implemented that meets the diverse needs of the community and their ability to access IT;
- the Charter should be accessible online and access well promoted;
- broad community engagement is essential to the success of the Charter;
- information for consumers needs to be given well in advance of hospitalisation or treatment;
- develop a brochure that includes consumer stories;
- a TV advertisement should be made to promote the Charter;
- use the TVs in GP clinics to advertise the Rights;
- doctors / hospitals to give people a brochure about the Charter as part of the initial consultation or admission pack;
- train peer ambassadors to talk to patients and groups;
- must be highlighted with accreditation processes and codes of conduct in all health settings.

SAHRN commented that implementation could include a media campaign, information in all doctors, treatment and waiting rooms and at admission.

HCA believes that implementation of the Charter must be properly resourced and that the HCSCC Advisory Council should have a key role in overseeing and monitoring implementation.

### *2. INDEPENDENT INDIVIDUAL ADVOCACY*

Many of the Rights enshrined in the Charter will depend on access to support and advocacy. It is a serious concern that South Australian health consumers do not currently have access to an independent advocacy service that can provide support to individuals.



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