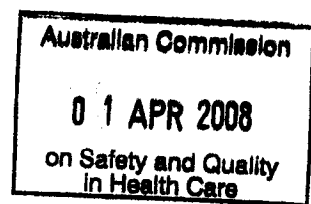


nsw commission for  
children & young people



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Professor Chris Baggoley  
Chief Executive  
Australian Commission on Safety and Quality in Health Care  
GPO Box 5480  
SYDNEY NSW 5480

Dear Professor Baggoley

I am pleased to enclose the NSW Commission for Children and Young People's submission to the Australian Commission on Safety and Quality in Healthcare on the *Draft National Patient Charter of Rights*.

I will be placing a copy of the submission on the Commission's website. Making work such as this publicly available is one mechanism I use to be accountable to children, young people and the Parliament of New South Wales.

If your staff require any further information, please contact the Commission's Manager, Policy, Dr Sharyn Jameson, on 9286 7205 or [Sharyn.Jameson@kids.nsw.gov.au](mailto:Sharyn.Jameson@kids.nsw.gov.au).

Yours sincerely

**Gillian Calvert**  
Commissioner  
27 March 2008

**SUBMISSION TO THE  
AUSTRALIAN COMMISSION ON QUALITY AND SAFETY IN  
HEALTH CARE  
DRAFT NATIONAL PATIENT CHARTER OF RIGHTS  
MARCH 2008**

**NSW Commission for Children and Young People  
Level 2, 407 Elizabeth Street  
Surry Hills NSW 2010**

**Contact: Sharyn Jameson, Manager, Policy  
Phone: (02) 9286 7205  
Fax: (02) 9286 7267  
Email: [kids@kids.nsw.gov.au](mailto:kids@kids.nsw.gov.au)**

# **SUBMISSION TO THE AUSTRALIAN COMMISSION ON SAFETY AND QUALITY IN HEALTH CARE**

**MARCH 2008**

## **1. The Commission for Children and Young People**

- 1.1. The NSW Commission for Children and Young People ('the Commission') promotes the safety, welfare and well-being of children and young people in NSW.
- 1.2. The Commission was established by the Commission for Children and Young People Act 1998 (NSW) ('the Act'). Section 10 of the Act lays down three statutory principles which govern the work of the Commission:
  - the safety, welfare and well-being of children are the paramount considerations;
  - the views of children are to be given serious consideration and taken into account; and
  - a co-operative relationship between children and their families and community is important to the safety, welfare and well-being of children.
- 1.3. Section 12 of the Act requires the Commission to give priority to the interests and needs of vulnerable children. Children are defined in the Act as all people under the age of 18 years.
- 1.4. Section 11(d) of the Act provides that one of the principal functions of the Commission is to make recommendations to government and non-government agencies on legislation, policies, practices and services affecting children.

## **2. General comments**

- 2.1. The NSW Commission for Children and Young People is pleased to make a submission to Australian Commission on Safety and Quality in Health Care on the Draft National Patient Charter of Rights.
- 2.2. The Commission congratulates the Australian Commission on Safety and Quality in Health Care on the development of the draft charter. As a framework for the delivery of health services the charter has potentially wide reaching impacts on the delivery of health services to all Australians, including, importantly children and young people.
- 2.3. The Commission's work with children and young people in recent years has highlighted various issues relating to the provision of health services in Australia. This submission will be informed by what children and young people in NSW have told us about their experiences of

wellbeing, health and health care in a number of forums. The *Ask the Children, Children and young people talk about Health* report can be found on the Commission's website at [www.kids.nsw.gov.au/kids/resources/publications/askchildren.cfm](http://www.kids.nsw.gov.au/kids/resources/publications/askchildren.cfm).

- 2.4. Between August 2005 and February 2006, the Commission spoke with over 200 children and young people aged 4 -18 years about what health means to them. This consultation was to inform the NSW Health Futures project, which set out to develop long term directions for the State's health system for the next 20 years. The consultations provided us with invaluable information on children and young people's perceptions of health and of health services.
- 2.5. This submission is based on this work and other Commission projects, including our study of Children's Understandings of Well Being; our response to the United Nations National Plan of Action, A World Fit for Children; our Report of an Inquiry into the Best Means of Assisting Children with No-one to Turn To; a submission to the NSW Parliamentary Inquiry into Children, Young People and the Built Environment; and consultations held with children and young people prior to the NSW Summit on Alcohol Abuse (2003).

### **3. National Patient Charter of Rights and National Patient Charter Principles**

- 3.1. The rights and underpinning principles contained in the Draft National Patient Charter of Rights consultation paper are supported. A National charter will provide overarching principles and guidelines for the development of state and jurisdiction charters.
- 3.2. As currently expressed both the charter and the principles are useful and clear. They should be actively promoted to the Australian community and to the universal health care system.
- 3.3. While the Commission supports the development of a National charter for patient rights, the term "patient" potentially limits the application of the charter to the acute end of the health system. It may be interpreted as limited to the rights and responsibilities of people who are sick. This could reduce the application of the charter to broader health service environments, such as those providing health promotion, prevention and early intervention services. As children and young people are more frequently in contact with these health care services, the focus on acute services implied by "patient" could result in their rights and responsibilities being given less consideration.
- 3.4. Rights and responsibilities are essential to health service delivery, but to be meaningful, they need to be able to be enacted. Health services need to be appropriate for children and young people, so they can achieve their right to health and well-being.

- 3.5. Article 24 of the Convention on the Rights of the Child defines the right of children to *the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health.*
- 3.6. While the charter and principles are suitable for use by adult patients and providers, their focus and language are adult-centred. They may not be easily understood by children.
- 3.7. It is recommended that age-appropriate resources are developed, based on the existing draft charter, to assist children, young people and the families understand their rights and responsibilities. Any resources for children and young people should be developed in partnership with children and young people, in accordance with the rights of participation and respect contained in the draft charter. The expertise of specialised children's health services, such as children's hospitals and child and youth health services, could be utilised to develop these resources.
- 3.8. The Commission on Safety and Quality in Health Care could consider developing a specific children and young's people charter to accompany the existing charter.
- 3.9. Services such as hospitals commonly display charters and patient rights and responsibility statements in public areas such as waiting rooms and foyers. Information resources specifically targeting children and their families should also be displayed in all health services and actively promoted by all health service staff.
- 3.10. As children and young people access information, including health information, from the internet, the charter should be available electronically and actively promoted to children and young people.

#### **4. Rights included in the charter**

- 4.1. The eight key patient rights expressed in the draft National Patient Charter are supported. Children and young people may need assistance in understanding and exercising these rights and responsibilities. This assistance is often provided by parents or family members who act as advocates for children, but some vulnerable groups, such as children without parent or family support, do not have access to this assistance.
- 4.2. The development of child friendly resources would assist health services in helping children understand what they are entitled to expect from services provided to them. Children and young people from culturally and linguistically diverse communities may have additional challenges in exercising their rights and responsibilities.

- 4.3. Health service providers may need additional training and support in communicating with children and enabling them to exercise their rights. Kids tell us that health providers often talk about them to their parents without telling kids what is going on.

#### **Access**

- 4.4. Children and young people primarily access services through their parents, who facilitate access and are often advocates for them in their relationships with health care services. The capacity of young people to access services will vary with age. As children grow they are more likely to seek access to services independently, particularly in regards to sensitive issues.
- 4.5. Young people have little understanding of how the system and individual services are financed. They say that they do not understand Medicare, private insurance, how to get a personal card, pay for a visit to a doctor, and/or claim a rebate. Not understanding how to pay for services, or knowing what they will cost, mean that young people are reluctant to use even basic services like GP consultations. For some young people, particularly those in rural areas, access to bulk billing general practitioners remains an issue.

*“A lot of young people can’t afford to pay to go see a service. That makes young people nervous, thinking “I’ve got no money, how am I going to pay?”* (boy, 17)

- 4.6. Many young people we spoke with during our consultations had not seen a health professional in several years. Many identified not having their own Medicare card as a barrier to access. As a result, some appear not to seek treatment at all. Some adolescents we spoke with cannot remember ever having visited a GP.

*“I don’t go to a GP. I haven’t been sick for 2 years. I get the flu and I get over it – there’s no time to go to the doctor. Mum doesn’t take me to the doctor unless I’m bleeding to death and vomiting my guts up everywhere”* (boy, 16)

#### **Respect, communication and information**

- 4.7. The rights of respect, communication and information are interrelated. Children and young people like face to face contact and need to be able to develop relationships with people who work in health, even if it’s just a short meeting. Young people tend to visit a person not a service: they go to see ‘Chris’, not to the diabetes clinic.
- 4.8. Children and young people react to practitioners talking to their parents about them, rather than to them. One of the ways that respect is shown to children and young people is via communication. It is possible to talk directly to quite young children and address them

personally. Similarly, older children and adolescents like to be addressed respectfully and warmly.

*"I like it when our doctor talks to me, but mostly he talks to mum and gives me a lolly at the end."* (girl, 6)

It is essential to provide age appropriate information and solicit feedback from children and young people to understand their opinions and preferences.

*"I leave not knowing anything"* (boy, 10)

- 4.9. Kids can be discouraged by a bad experience with the health system. If they find their contact unhelpful, embarrassing or perplexing, they will be reluctant to use services again.

*"I went into hospital at 5pm and waited till 6am to be seen to – it was a broken leg, and only one Panadol was given to me in the mean time"* (girl, 14)

At present, the encounters between children and health care providers can sometimes strike children as an alien, highly specialised, painful and time consuming experience, to be avoided in future.

*"I was scared because I went to have my appendix out, and I wasn't quite sure what was happening, and I couldn't walk the next morning."* (boy, 9)

- 4.10. There is scope for making these encounters more comprehensible and less stressful, through respect, communication and information provision so children develop a better understanding of how health services can be helpful, less frightening and more approachable.

### **Safety**

- 4.11. Concepts such as safety mean different things to children and young people than they do for adults. For example, an adult centred understanding of safety for children in hospital may be about keeping children safe from predatory adults whereas some children have told us that sharing wards with sick old people makes them feel unsafe.

*"I was scared because there were all these people with like, half an eye"* (boy, 10)

### **Participation**

- 4.12. The principle of participation is very important for children and young people. Children and young people need to be treated as individuals and to participate in discussions that concern them. Even young children prefer to participate in decisions that affect their lives

*“Children should have a say in how they receive advice about their health and which services they receive. This is because they would feel more comfortable and would be more likely to use these services.”*  
(boy, 14)

- 4.13. A principal function of the Commission is to promote the participation of children in the making of decisions that affect their lives. We have produced a resource kit to assist organisations to involve children and young people better in their work. The *TAKING PARTicipation seriously* kit is available at <http://www.kids.nsw.gov.au/kids/resources/participationkit.cfm>.

#### **Privacy**

- 4.14. Privacy is very important to young people. The points listed under this principle in the consultation draft focus on the safety, storage and sharing of information. While these are important issues to address, when we speak with children and young people they raise different privacy concerns.
- 4.15. Concerns about confidentiality sometimes prevent them from using health services. Young people with sexual health problems or other “sensitive” health issues will visit a health practitioner they and their family have never used before, as a result of concerns about their family finding out. This is particularly the case in small rural towns and for children who live in one culture at home and a different culture in their social life outside the home.
- 4.16. Many adolescents have deliberately chosen to visit a GP not linked to their family and outside their culture in order to preserve privacy and anonymity.

*“I would do some research on the net first and then go to a non-Korean GP”*  
(girl, 16)

- 4.17. Young people staying in hospital have also told us that they will sometimes need privacy. Ward accommodation needs to be flexible enough to provide personal space when needed. Ideally children should not be located in adult wards.

*“You don’t want to watch old people die around you. Old people tend to be much sicker”*  
(girl, 11)

#### **Redress**

- 4.18. The right of redress as expressed in the paper is unlikely to be understood by children. It would benefit from rewording and further explanation in a child-friendly style. Children and young people may need help to raise concerns about services. They rarely make complaints to people or organisations they do not know. For this right to be realised, health services may need to actively seek feedback from children and young people about their satisfaction with services,

rather than wait for them to complain.

## **5. Points included in the principles**

- 5.1. The points included in the principles are supported. They may be couched in simpler language to be easily understood by children and young people.
- 5.2. The points included in the principles are clear and applicable to children and young people. However, they are predominantly adult-centred in concepts and explanation.
- 5.3. The Commission has developed a set of operating principles for health services, based on feedback from children and young people about their own health, their experiences of the health system and what they would like to see in a healthy world. These principles are translatable to other types of service for children and young people, not just those based in the traditional health system:
  - Focus more on children and young people
  - Help children and families manage their own health
  - Provide services close to children and young people
  - Provide services that are personalised and individualised
  - Communicate directly with children and young people
  - Communicate in new ways

The principles above align with the charter principles expressed in the consultation paper.

## **6. Rights and responsibilities**

- 6.1. The current mix of rights and responsibilities in the draft is appropriate. Children and young people are often dependant on others, so their responsibilities can be less than those of adults.
- 6.2. As children grow and develop, they assume more responsibility for decisions in their lives, including decisions about their health.

*“As I was growing up I had a family doctor. When I was old enough to realise he was quite silly I went out and found a doctor I liked and can communicate with.”* (girl, 17)

- 6.3. The right to health influences other rights for children and young people, importantly the right to education. Children and young people with chronic health conditions risk having their education compromised by frequent hospital stays or periods of ill health.
- 6.4. The responsibility for making sure that children and young people are able to obtain their rights potentially rests with services providers,

families and, in some cases the broader community, who need to work in partnership with each other and children and young people.

## **7. Existing charters**

- 7.1. The Australian Research Alliance for Children and Youth has developed a commitment to Young Australians, [http://www.aracy.org.au/AM/Template.cfm?Section=Sign\\_Up\\_Now&Template=/CM/HTMLDisplay.cfm&ContentID=2997](http://www.aracy.org.au/AM/Template.cfm?Section=Sign_Up_Now&Template=/CM/HTMLDisplay.cfm&ContentID=2997) . The Commitment contains seven principles which are compatible with those in the consultation draft.
- 7.2. Charters of rights exist in most states for children and young people in out of home care. The NSW charter is available at [http://www.community.nsw.gov.au/DOCS/STANDARD/PC\\_100213.html](http://www.community.nsw.gov.au/DOCS/STANDARD/PC_100213.html). The charter includes the right to services that promote health and well-being. The charter is produced in formats that are targeted for children and young people and may provide a useful resource for the committee.

## **8. Possible uses of the charter**

- 8.1. The ways the Charter and Principles are used are as important as the content of these documents.
- 8.2. Health services can be seen as unfriendly by children and young people. This may be in part because the bulk of patients in acute services, the most visible service users, are adults. Since the determinants of ongoing health are established in childhood, it is important health services are acceptable, accessible and responsive to children and young people. A charter of rights that addresses the rights of children and young people has the potential to a more inclusive culture and support the creation of child-friendly environments.
- 8.3. There are specialist providers of health services to children and young people who provide excellent services and are models for child-friendly service provision. The existence of specialist services does not lessen the need for generalist services to improve provision to children and young people.
- 8.4. The Charter and Principles potentially have a broad role in standard setting, accreditation, education and training. It is likely that services will require training in order to implement the charter. This is particularly important when considering the rights of children and young people. The Commission supports the inclusion of modules on appropriate service delivery to children and young people in all health care settings providing services to children and young people. This