



# *Report on CHA Project on the Rights of Children and Young People in Healthcare Services*

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Project Expert Reference Group*

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## Contents

Background .....	1
Project Objectives .....	1
Expert Reference Group (ERG).....	2
Writing Subcommittee .....	2
The Self-Evaluation Survey.....	3
Overview .....	3
Results of the self-evaluation .....	6
Considerations for the future .....	22
The Charter .....	23
Rationale.....	23
Process.....	23
Principles of the Charter .....	24
Breadth of the Charter .....	24
The Rights .....	25
Launch of the Australian version of the Charter .....	26
Launch of the New Zealand version of the Charter.....	27
Forum.....	28
Recommendations from the project/Future actions.....	30
Acknowledgments.....	32
APPENDIX 1: Rights for children: Australian Version .....	33
APPENDIX 2: Rights for children: New Zealand Version .....	34
APPENDIX 3: Poster for children .....	35
APPENDIX 4: Rights for young people: Australian Version .....	36
APPENDIX 5: Rights for young people: New Zealand Version .....	39
APPENDIX 6: Poster for young people .....	42
APPENDIX 7: Publications .....	43
APPENDIX 8: Conference presentations/submissions .....	44

## Background

In November 1989 the *United Nations Convention on the Rights of the Child* (UNCRC) was opened for signature and was ratified by Australia in the months that followed.

A large number of the articles of the UNCRC apply to aspects of clinical care and health services. The *International Taskforce on Health Promotion for Children and Adolescents in and by Hospitals and Health Services* commenced work in 2004 towards the development of a *Self Evaluation Model and Tool on the Respect of Children's Rights in Hospitals and Health Services*. Professor Les White AM (previously President of Children's Hospitals and Paediatric Units Australasia (CHA)) worked with the Taskforce and with piloting the Model and Tool in Australia.

In early 2010, the year of the 21st anniversary of the UNCRC, the CHA Board initiated a project on children's and young people's rights in healthcare services. Professor White chaired the Expert Reference Group (ERG) to oversee this project.

## Project Objectives

The objectives for the CHA project on children's and young people's rights in health care services were to:

- Oversee the process of CHA member health services participating in a self evaluation survey on the respect of children and young people's rights in their services. This survey is part of a broader initiative undertaken by the Child and Adolescent Taskforce of the Health Promoting Hospitals (HPH) international collaboration. The aim of this exercise is for each health service to analyse and reflect on children's rights in their service, to understand best practices and to provide a basis and guide for further improvement.
- Develop a *CHA Charter of Rights for Children and Young People in Healthcare Services in Australia and New Zealand*.
- Establish formal relationships with the HPH networks in Australia, New Zealand and internationally, and promote to health services the process required for health services to achieve WHO accreditation as a HPH.
- Hold a workshop in Melbourne in November 2010 on *The Rights of Children and Young People in Healthcare Services* to celebrate the 21st anniversary of the UNCRC.

## Expert Reference Group (ERG)

**Chair: Professor Les White AM**, Chief Paediatrician NSW

### Members

**Lauren Andrew**, Director of Allied Health, Royal Children's Hospital, VIC

**Virginia Binns**, Clinical Director, Community and Ambulatory Care, Sydney Children's Hospital, NSW

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**Anne Cutler**, Program Manager, Association for the Wellbeing of Children in Healthcare (AWCH)

**Professor Patricia Davidson**, Area Director Kaleidoscope, John Hunter Children's Hospital, NSW

**Elizabeth Harnett**, Head of the Service Improvement Unit, The Children's Hospital at Westmead, NSW

**Elizabeth Kepreotes**, Health Manager - Clinical Improvement, John Hunter Children's Hospital, NSW

**Bruce Lord**, Clinical Program Chair (Ambulatory & Emergency), The Children's Hospital at Westmead, NSW

**Anne Morgan**, Service Manager - Child Health, Canterbury District Health Board, NZ

**Joyce Murphy**, Consumer Participation Coordinator, The Children's Hospital at Westmead, NSW

**Dr Shanti Raman**, Area Community Paediatrician-Child Protection, Sydney South West Area Health Service, NSW

**Stephen Simpson**, Director of Paediatric Nursing, Canberra Hospital, ACT

**Paul Watson**, Clinical Nurse Educator, Child Health, Christchurch Hospital, New Zealand

**Dr Karen Zwi**, Community Paediatrician, Sydney Children's Hospital, NSW

### *Writing Subcommittee*

**A/Professor Judith Duncan**, Associate Professor of Education, University of Canterbury, NZ

**A/Professor Lynn Gillam**, Associate Professor, The University of Melbourne, VIC

**Elizabeth Harnett**, Head of the Service Improvement Unit, The Children's Hospital at Westmead, NSW

**Ros McDougall**, Writer, Brunswick, VIC

**Joyce Murphy**, Consumer Participation Coordinator, The Children's Hospital at Westmead, NSW

**Paul Watson**, Clinical Nurse Educator, Child Health, Christchurch Hospital, New Zealand

## The Self-Evaluation Survey

### Overview

#### *Development of the Self-Evaluation Model and Tool and its implementation in Australasia*

The *Self Evaluation Model and Tool on the Respect of Children's Rights in Hospitals and Health Services* is an evaluation model and self-assessment tool for paediatric hospitals and health care facilities, or general hospitals with a large paediatric unit, to help them measure how well they recognise and promote the rights of children and young people.

The twelve rights in the self-evaluation model are based on the UNCRC, the *European Association for Children in Hospital Charter* and the *Charter of the International Children's Palliative Care Network*.

**TABLE 1. LIST OF RIGHTS IN THE SELF-EVALUATION MODEL AND TOOL ON THE RESPECT OF CHILDREN'S RIGHTS IN THE HEALTHCARE SETTING.**

AREA 1. Right to the highest attainable standard of health care.	
Right 1.1	Children's health care provision should take into consideration all dimensions of health, including physical, mental, social, cultural and spiritual.
Right 1.2	Children have the right to access health services without ethnic, racial, class, religious, gender, age, sexual orientation, disability, language, cultural and social discrimination.
Right 1.3	Children shall be admitted to the hospital only if the care they require cannot be equally well provided and effective at home or on a day basis.
Right 1.4	Children have the right to have full opportunity for play, rest, leisure, recreation and education suited to their age and condition and to be in an environment designed, furnished, staffed and equipped to meet their needs.
AREA 2. Right to information and participation in all decisions involving their health care.	
Right 2.1	Children have the right to be informed in a manner appropriate to their age, developmental level and understanding.
Right 2.2	Children have the right to express freely their opinions on any issue that involves them and the right to be heard and to be taken into consideration in a way consistent with their age and maturity.
AREA 3. Right to protection from all forms of violence.	
Right 3.1	Children have the right to be protected from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse.
Right 3.2	Children have the right not to be separated from their parents/guardians/caregivers against their will during their stay in hospital.
Right 3.3	Children have the right to privacy.
Right 3.4	Children have the right to a dignified death.
Right 3.5	Children have the right not to feel pain.
Right 3.6	Children have the right not to be submitted to clinical research or experimentation projects and to have the possibility to withdraw during the process of research.

In 2010, CHA invited its 28 member organisations to participate in a benchmarking exercise using the self-evaluation model and assessment tool. Eleven members, representing 15 facilities across Australia and New Zealand, accepted the invitation. Participating facilities were provided with the self-evaluation tool and reporting template.

***TABLE 2. LIST OF FACILITIES IN AUSTRALIA AND NEW ZEALAND THAT PARTICIPATED IN THE INAUGURAL SELF-EVALUATION ON THE RIGHTS OF CHILDREN AND YOUNG PEOPLE IN THE HEALTHCARE SETTING.***

<i>Name of Facility</i>	<i>Type of Facility</i>	<i>Location</i>
The Children's Hospital at Westmead	Tertiary Paediatric Hospital	NSW
Children, Youth and Women's Health Service	Tertiary Paediatric Hospital	SA
John Hunter Children's Hospital	Tertiary Paediatric Hospital	NSW
Royal Children's Hospital, Brisbane	Tertiary Paediatric Hospital	QLD
Royal Children's Hospital, Melbourne	Tertiary Paediatric Hospital	VIC
Sydney Children's Hospital	Tertiary Paediatric Hospital	NSW
Gold Coast Hospital	General Hospital with a paediatric wing	QLD
Christchurch Hospital	General Hospital with a paediatric wing	NZ
Canterbury Hospital	General Hospital with a paediatric wing	NSW
Liverpool Hospital	General Hospital with a paediatric wing	NSW
Frankston Hospital	General Hospital with a paediatric wing	VIC
Kaleidoscope	Community Health Centre	NSW
Canterbury Community Health	Community Health Centre	NSW
Liverpool Community Health	Community Health Centre	NSW
Youth Mental Health	Community Health Centre	VIC

The Children's Hospital at Westmead collated all responses from the 15 facilities on behalf of CHA.

### ***Self-evaluation methodologies***

There was no prescribed process for facilities to complete the self-evaluation. Each facility was able to undertake the self-evaluation in the way most suited to its organisation, existing structures and resources (Table 3).

**TABLE 3. LIST OF FACILITIES IN AUSTRALIA AND NEW ZEALAND AND A BRIEF DESCRIPTION OF THE METHODOLOGY ADOPTED TO COMPLETE THE SELF-EVALUATION.**

<b><i>Name of Facility</i></b>	<b><i>Methodology</i></b>
<b>The Children's Hospital at Westmead</b>	Staff were asked to provide evidence via email on rights relevant to their department. Consultation occurred with the Youth Advisory Council and Family Advisory Council as well as a member of staff.
<b>Children, Youth and Women's Health Service</b>	Three meetings, one with parents and two with staff over a month.
<b>John Hunter Children's Hospital &amp; Kaleidoscope</b>	Multidisciplinary working group that met five times over a four month period.
<b>Royal Children's Hospital, Brisbane</b>	Series of meetings with various staff and members of the Family Advisory Council and Youth Advisory Council.
<b>Royal Children's Hospital, Melbourne &amp; Youth Mental Health</b>	Overseen by steering committee comprised of executive staff.  Staff Evaluation Group – 3 sessions were required to collect the data. This was offered with 6 sessions for staff over 6 weeks.  Youth Advisory Committee – 1 session of 1.5 hours was held with a modified version of the self-audit tool. An adolescent manager assisted with preparation of questions to ensure language and content was adolescent accessible.  Family Advisory Council – An on line survey was sent to members. This survey was modified from the self-assessment tool.
<b>Sydney Children's Hospital</b>	Multi-disciplinary working group including members of the Parent & Consumer Council, which met five times in a four month period; focus groups with children and young people.
<b>Gold Coast Hospital</b>	Multi-disciplinary working group that met once.
<b>Christchurch Hospital</b>	Staff invited to provide input to the self-evaluation via three online surveys; at least 43 staff took part in the surveys. The nurse educator and service manager met twice to discuss survey results. Members of the Family Advisory Council also provided input.
<b>Canterbury Hospital &amp; Community Health</b>	Multidisciplinary working group that met four times over a three month period.
<b>Liverpool Hospital &amp; Community Health</b>	Multidisciplinary working group which also contained representatives from the Patients' Association. The working group met four times over a three month period.



## Results of the self-evaluation

### Overall ratings of each right

As part of the self-evaluation, each facility was required to rate their compliance with each right against a four-point scale (Table 4).

***TABLE 4. RATING SCALE USED IN THE SELF-EVALUATION WITH A DESCRIPTION OF EACH RATING.***

Rating	Definition
<b>Completely unconsidered</b>	There are few, if any, examples that show that this right is being considered and that work is being done in order to implement it.
<b>Slightly considered</b>	The need is recognised but there has been little or no action yet. There are not yet examples of consideration for this right, but an approach is being developed; or there are isolated examples of this right being addressed.
<b>Meaningful progress</b>	We have made significant progress towards addressing this right. The methods are now evaluated and mature and we increasingly look for further development and adaptation. This is increasingly seen by staff as 'part of the job'. The activities in this area are usually, though not always integrated.
<b>Significantly achieved</b>	Recognition of the right is integral to hospital/ward activities. All staff recognise its importance and are committed to its promotion. There is an effort for continuous improvement.

The greatest number of 'significantly achieved' ratings (13) was for Right 3.6, 'Children have the right not to be submitted to clinical research or experimentation projects and to have the possibility to withdraw during the process of research'.

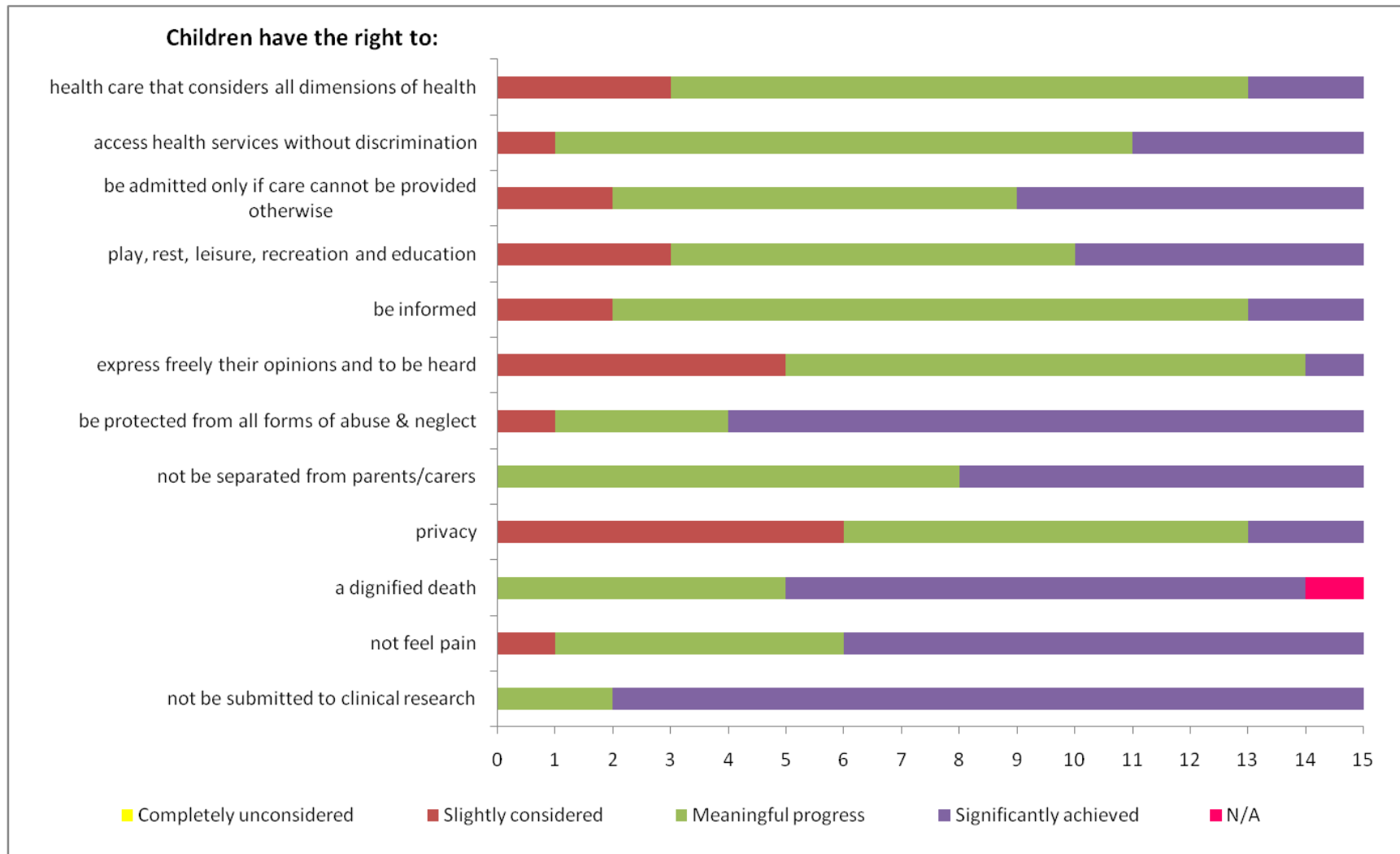
The lowest number of 'significantly achieved' ratings (1) was for Right 2.2, 'Children have the right to express freely their opinions on any issue that involves them and the right to be heard and to be taken into consideration in a way consistent with their age and maturity'.

The right which had the highest number of 'slightly considered' (7) was Right 3.3, 'Children have the right to privacy'.

No facility gave themselves a rating of 'completely unconsidered' on any of the rights.

Figure 1 shows the overall ratings for each of the rights.

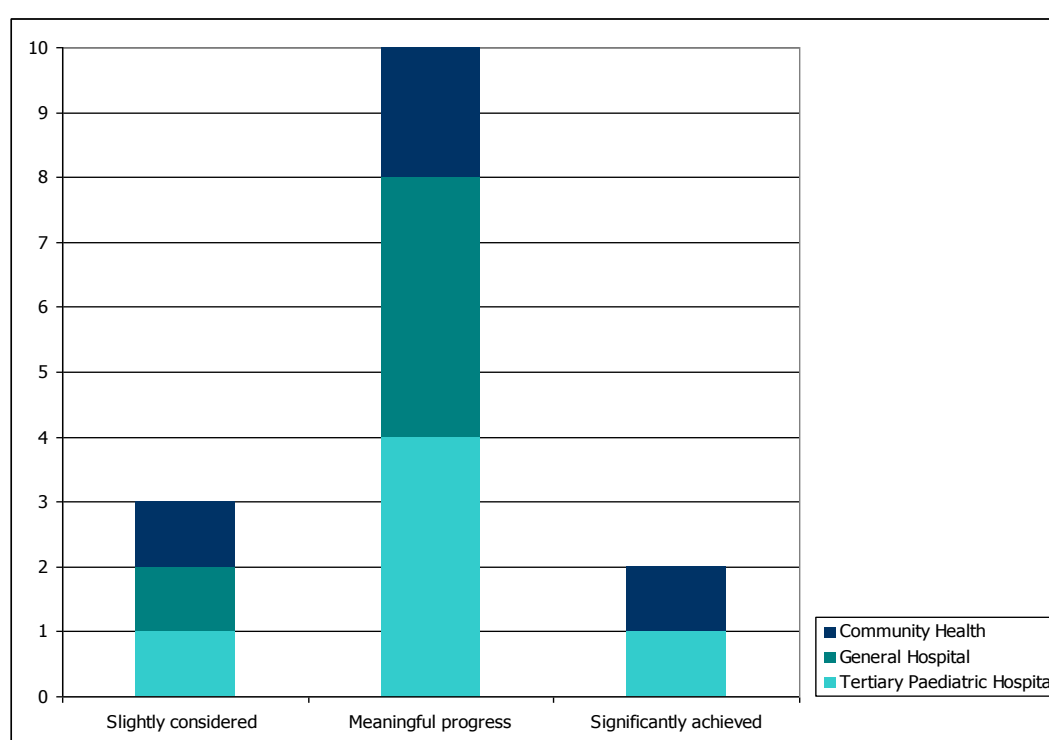
**FIGURE 1. THE OVERALL RATINGS FOR EACH RIGHT**



### Individual ratings and evidence for each right

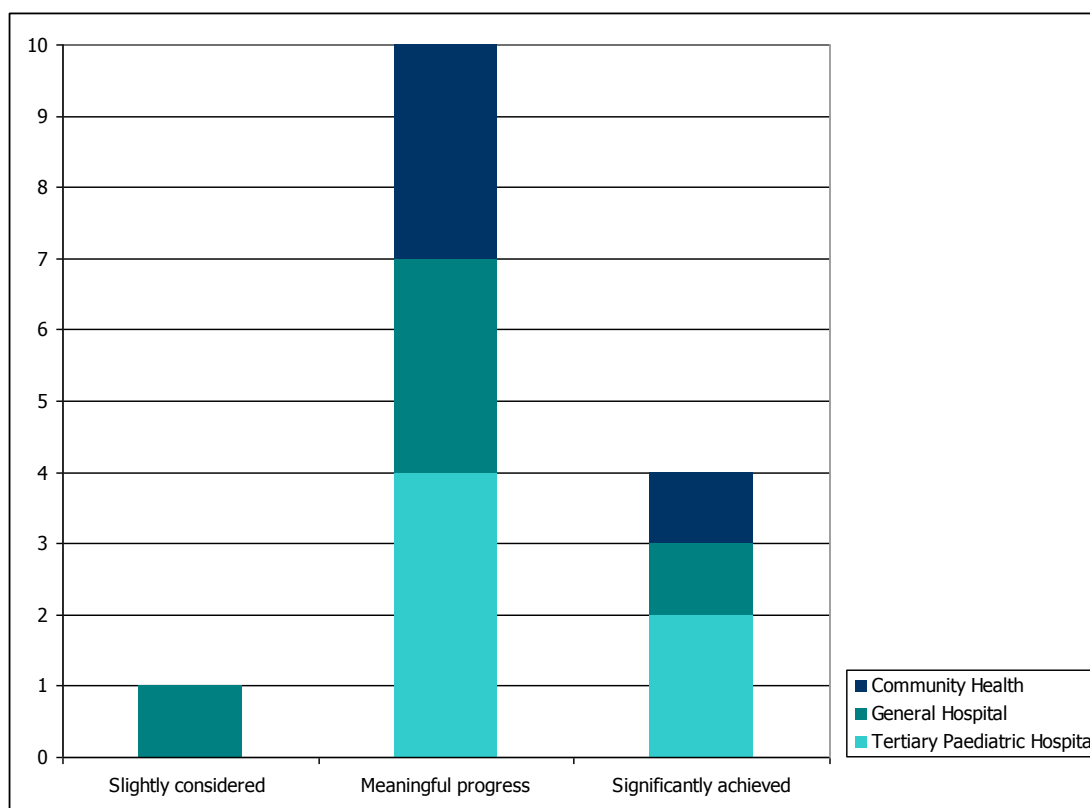
In support of their evaluation and rating for each right, participating facilities were required to describe their organisation's strong points (or good practices), areas for improvement and future activities in relation to each right. There were few areas of commonality which meant it was not possible or useful to theme the responses. The information provided in the table under each of the rights in this section is a summary of the responses, rather than themes. The overall evaluations are split by facility type, to enable comparison of ratings between tertiary paediatric hospitals, general hospitals and community health organisations.

**Right 1.1: Children's health care provision should take into consideration all dimensions of health, including physical, mental, social, cultural and spiritual**



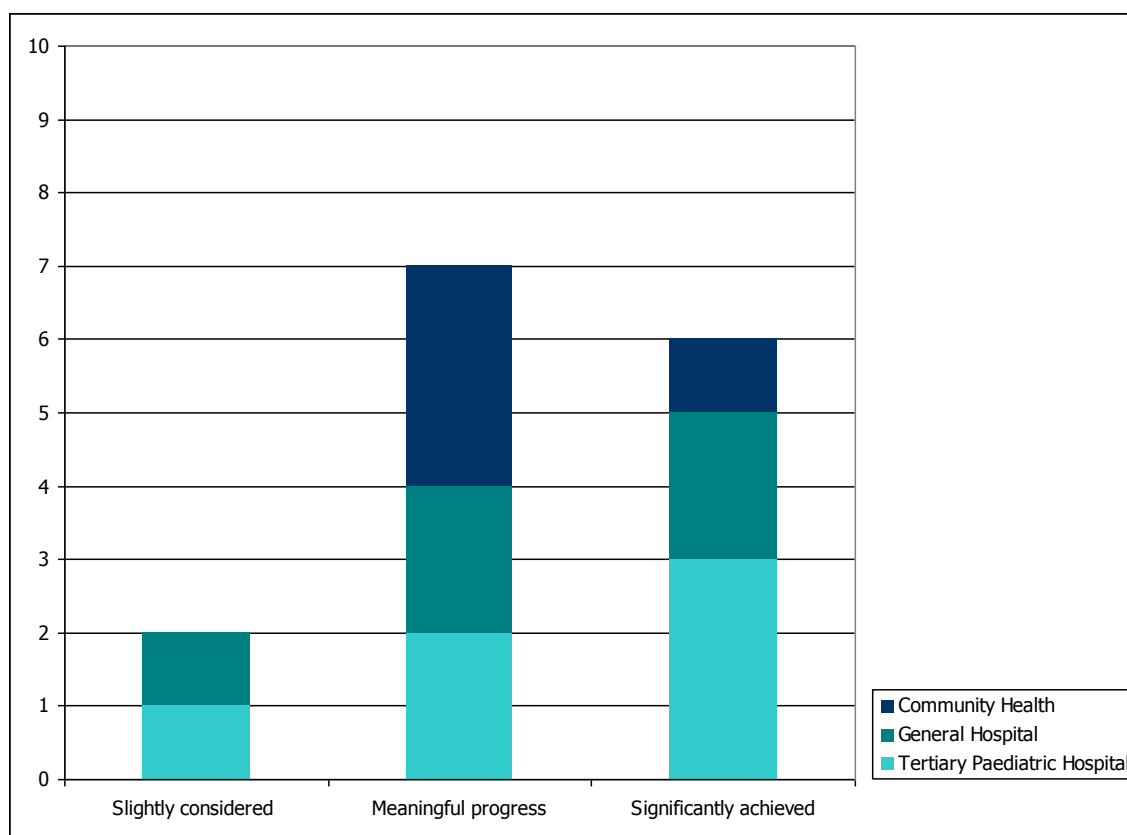
Good Practices	Areas for Improvement	Future Action
<ul style="list-style-type: none"> <li>• Availability and use of interpreters</li> <li>• Cultural awareness training</li> <li>• Aboriginal, Maori &amp; multicultural health workers</li> <li>• Social workers and counselling</li> <li>• Facilities for Aboriginal families</li> <li>• Holistic approach to health care</li> <li>• Integrated mental health care</li> <li>• Allied health care</li> <li>• Space to record some demographic info</li> <li>• Hospital design is child-friendly</li> </ul>	<ul style="list-style-type: none"> <li>• Adults occupying beds in children's wards</li> <li>• Psychosocial needs of young people not being addressed</li> <li>• No designated adolescent beds</li> </ul>	<ul style="list-style-type: none"> <li>• Improve services for adolescents</li> <li>• Separating children and adults on wards</li> <li>• Charter of children's rights</li> </ul>

**Right 1.2: Children have the right to access health services without ethnic, racial, class, religious, gender, age, sexual orientation, disability, language, cultural and social discrimination.**



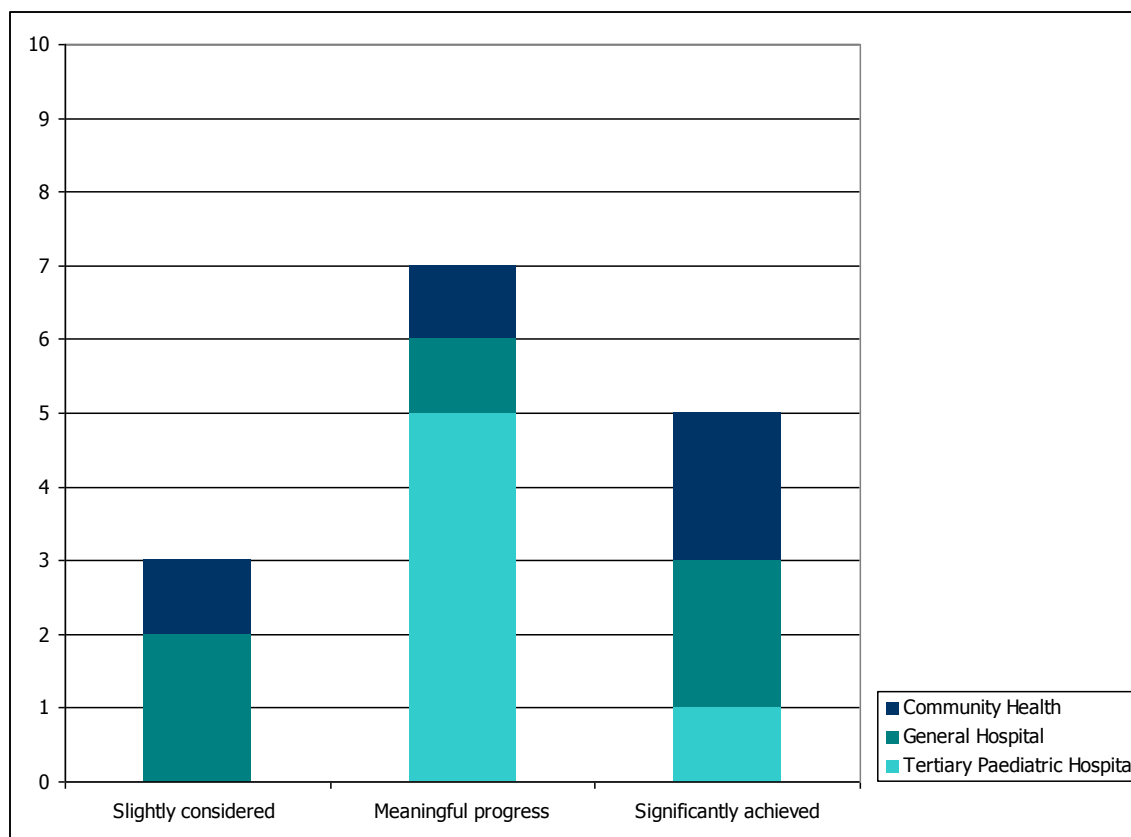
Good Practices	Areas for Improvement	Future Action
<ul style="list-style-type: none"> <li>Cultural competence training</li> <li>Aboriginal, Maori and multicultural health workers</li> <li>Services for families from particular cultures</li> <li>Access to interpreters</li> <li>Quiet/prayer rooms</li> <li>Multi-denominational chaplaincy service</li> <li>Refugee clinic</li> </ul>	<ul style="list-style-type: none"> <li>Mandated cultural competence training</li> <li>Improved food options</li> <li>Improve facilities for children with disabilities</li> <li>Written information available in community languages</li> </ul>	<ul style="list-style-type: none"> <li>Mandatory cultural competency training</li> <li>Signage and resources in other languages</li> </ul>

**Right 1.3: Children shall be admitted to hospital only if the care they require cannot be equally well provided and effective at home or on a day basis.**



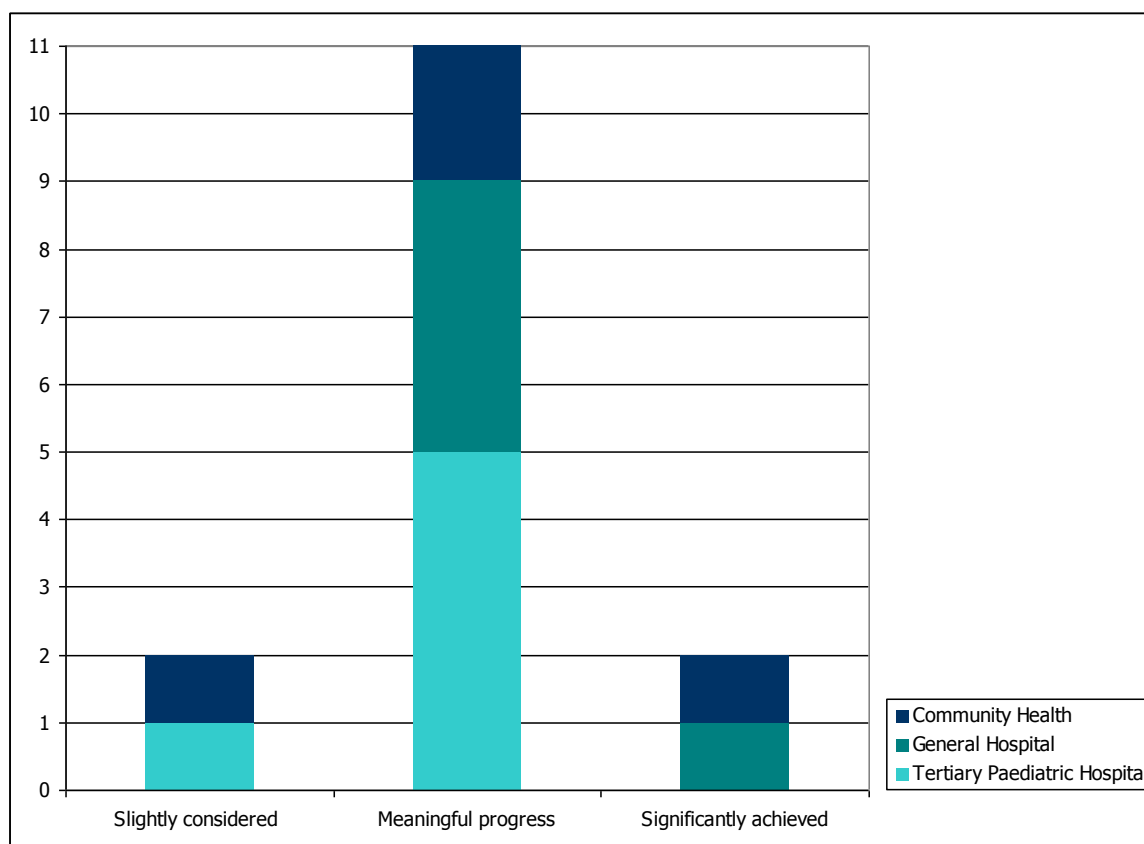
Good Practices	Areas for Improvement	Future Action
<ul style="list-style-type: none"> <li>Programs/policies to prevent and reduce hospitalisation, including outreach nursing</li> <li>Day surgery</li> <li>Care at home</li> <li>Collaborative work with community health services</li> <li>Hospital policy and protocols re admission</li> <li>Health promotion</li> </ul>	<ul style="list-style-type: none"> <li>Improve capacity of and relationships with primary care providers and regional services</li> <li>Better data re avoidable admissions etc</li> </ul>	<ul style="list-style-type: none"> <li>Improved data collection</li> <li>Development/expansion of hospital at home</li> <li>Discharge and outreach health services</li> <li>Monitoring home care</li> </ul>

***Right 1.4: Children have the right to have full opportunity for play, rest, leisure, recreation and education suited to their age and condition and to be in an environment designed, furnished, staffed and equipped to meet their needs.***



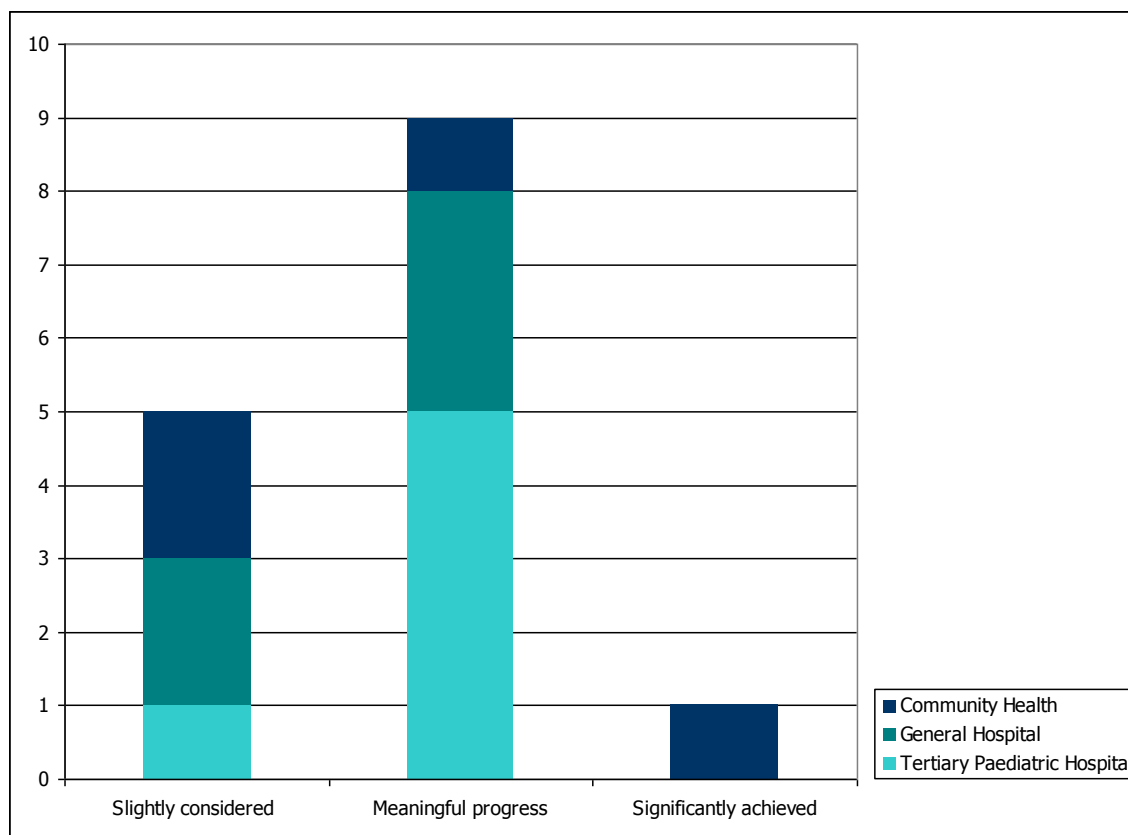
Good Practices	Areas for Improvement	Future Actions
<ul style="list-style-type: none"> <li>• Child friendly areas</li> <li>• Availability of other children's services – i.e. Starlight Foundation, Clown Doctors etc</li> <li>• Availability of hospital school</li> <li>• Play therapy</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of child friendly areas</li> <li>• Lack of play/music therapy</li> <li>• Lack of adolescent areas</li> <li>• Limited or no access to play therapy for outpatients</li> <li>• Limited options for medically isolated children and young people</li> </ul>	<ul style="list-style-type: none"> <li>• Better access to play specialist and play equipment</li> <li>• Increased resources for provision of children's education</li> <li>• Specific area to be provided for youth</li> <li>• Play spaces for children with IV poles and in beds</li> <li>• Emphasis on adolescents</li> </ul>

**Right 2.1: Children have the right to be informed in a manner appropriate to their age, developmental level and understanding.**



Good Practices	Areas for Improvement	Future Actions
<ul style="list-style-type: none"> <li>Clinicians happy to talk to children about their treatment/condition etc</li> <li>Availability of child appropriate resources</li> <li>Family centred care</li> <li>Involvement of children in consent</li> </ul>	<ul style="list-style-type: none"> <li>Establish and display a Charter of Rights</li> <li>Staff training re communicating with children</li> <li>Communication with children who require/use alternate communication systems</li> </ul>	<ul style="list-style-type: none"> <li>Training/education of staff</li> <li>Children's Health Charter/Rights and Responsibilities</li> </ul>

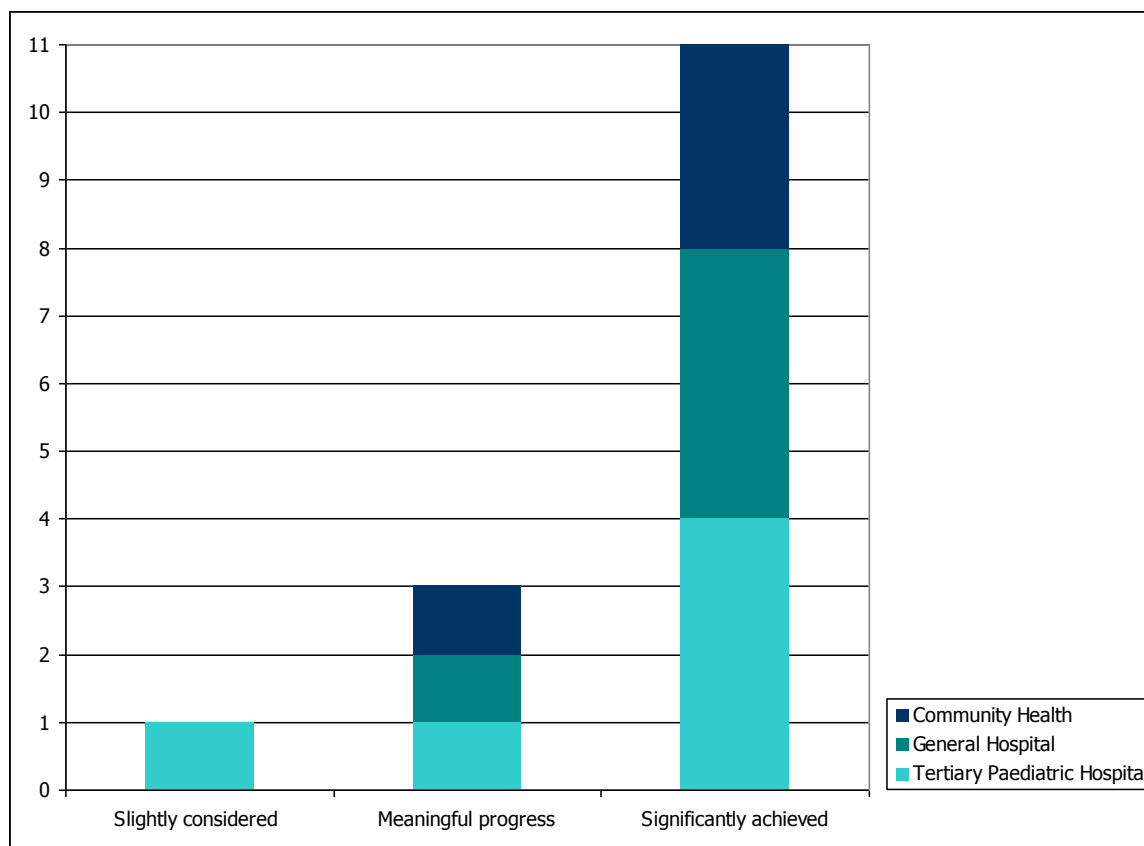
**Right 2.2: Children have the right to express freely their opinions on any issue that involves them & the right to be heard and to be taken into consideration in a way consistent with their age and maturity.**



Good Practices	Areas for Improvement	Future Actions
<ul style="list-style-type: none"> <li>• Involvement of children and young people in projects and committees</li> <li>• Complaints processes</li> <li>• Discussions with children regarding their treatment etc</li> </ul>	<ul style="list-style-type: none"> <li>• Nowhere for child's/young person's view to be recorded in clinical record</li> <li>• Patients and families not always aware of their rights</li> <li>• Better ways to communicate with children who are non-verbal</li> </ul>	<ul style="list-style-type: none"> <li>• Child friendly feedback tool</li> <li>• Create space in clinical record to note patient feedback/conversations.</li> <li>• Focus groups to give children and young people the opportunity to express their views</li> <li>• Raise awareness amongst staff and families</li> </ul>

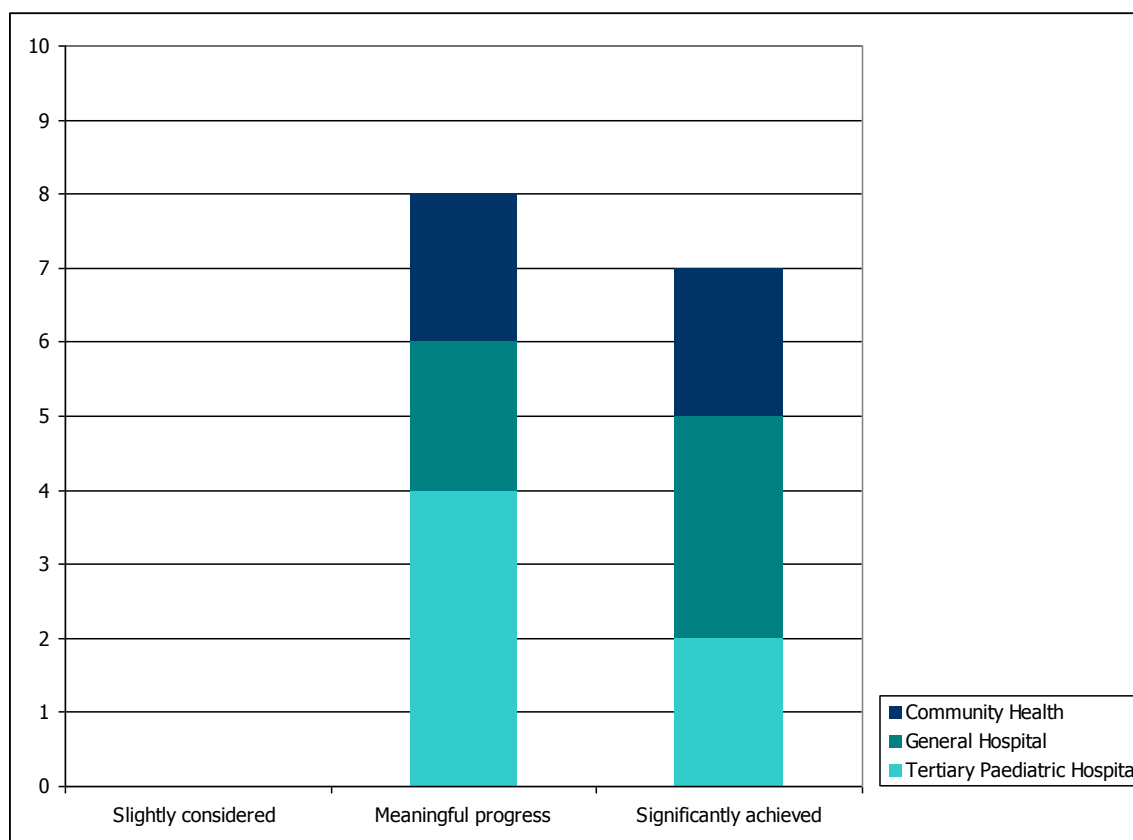


**Right 3.1: Children have the right to be protected from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse.**



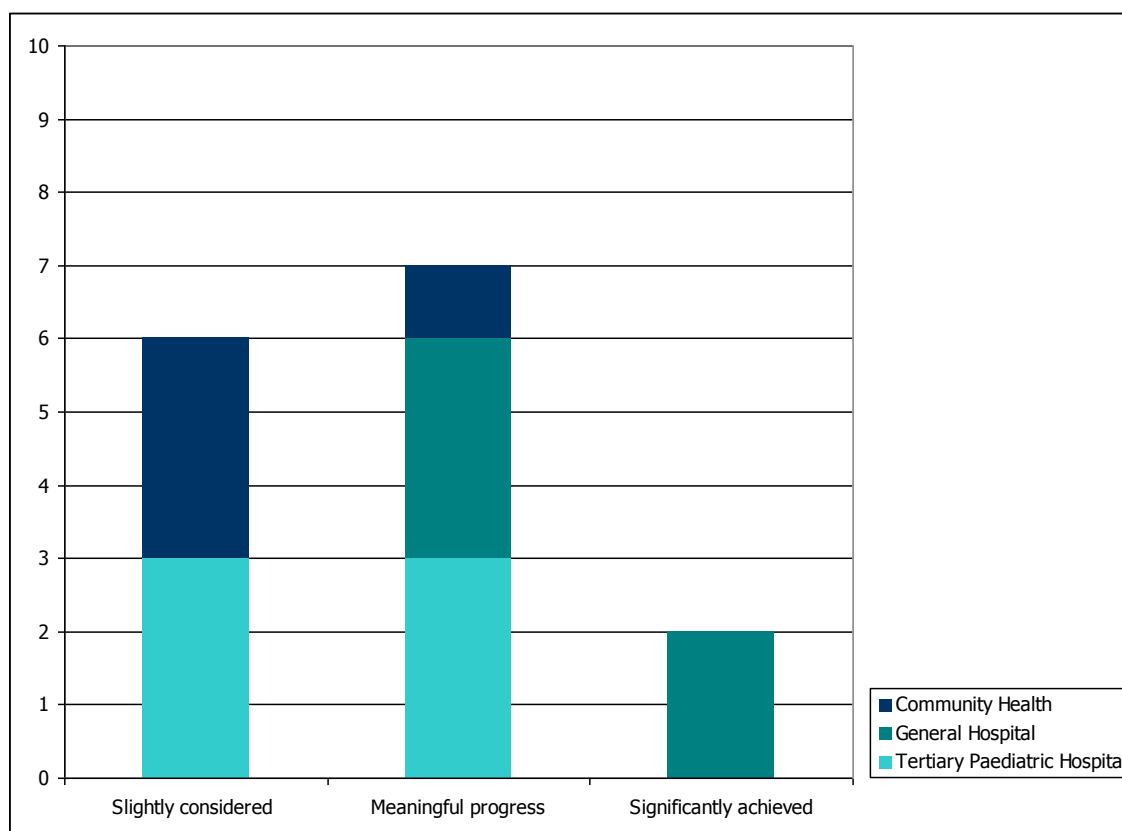
Good Practices	Areas for Improvement	Future Actions
<ul style="list-style-type: none"> <li>Child protection team/unit</li> <li>Child protection training, generally mandatory</li> <li>Child protection policies/guidelines</li> <li>Mandatory reporting</li> <li>Compliance with legislative requirements</li> </ul>	<ul style="list-style-type: none"> <li>Lack of clear guidelines</li> <li>Children in same areas as adults eg emergency, diagnostic rooms</li> <li>Staff training</li> <li>Updating policies</li> <li>Finding a balance between child safety and adults' access to wards</li> </ul>	<ul style="list-style-type: none"> <li>New policies</li> <li>Ongoing training and raising awareness</li> <li>Monitoring of mandatory reports</li> </ul>

**Right 3.2: Children have the right not to be separated from their parents/guardians/caregivers against their will during their stay in hospital.**



Good Practices	Areas for Improvement	Future Actions
<ul style="list-style-type: none"> <li>Family-centred care philosophy</li> <li>One parent/carer able to stay by the bedside overnight</li> <li>Parents/carers have round the clock access to their child</li> <li>Meals given to breastfeeding mothers</li> <li>Parents/carers able to be with their child in theatre up to anaesthesia</li> </ul>	<ul style="list-style-type: none"> <li>No room to sleep by the bedside in ICU</li> <li>Meals for parents</li> <li>More facilities for parents</li> <li>Space for both parents to sleep by the bedside</li> </ul>	<ul style="list-style-type: none"> <li>Meals for parents</li> <li>Accommodation by the bedside</li> <li>Ward grannies scheme</li> <li>Family rooms</li> </ul>

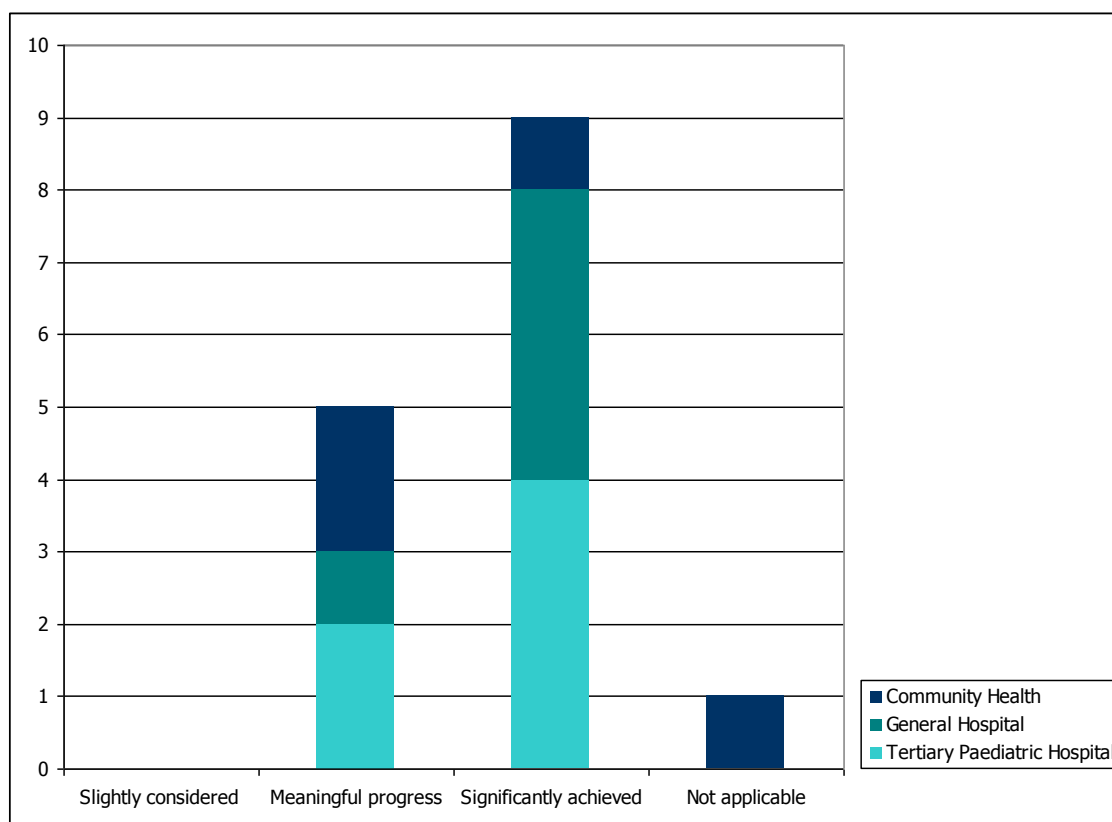
**Right 3.3: Children have the right to privacy.**



‘Privacy’ was generally taken to mean information privacy as well as physical privacy.

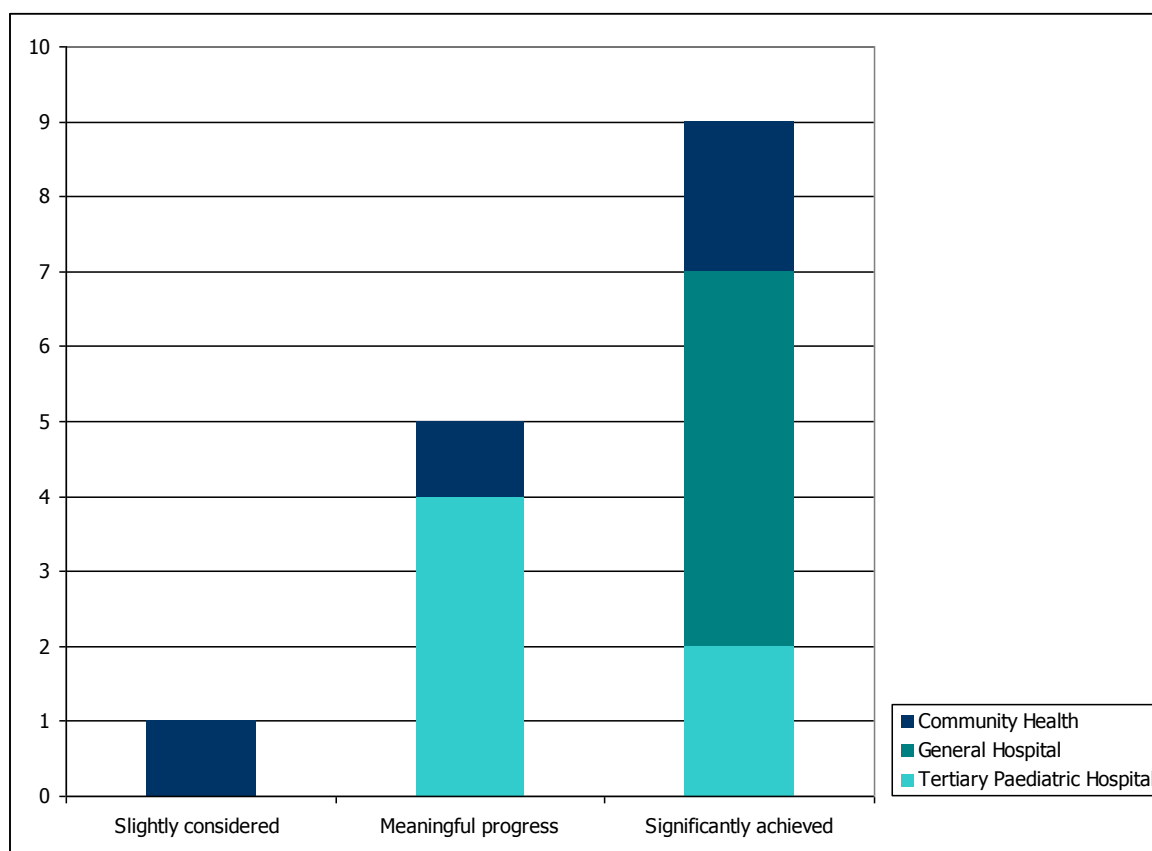
Good Practices	Areas for Improvement	Future Actions
<ul style="list-style-type: none"> <li>• Curtains for privacy during examinations/procedures</li> <li>• Adolescents separated by gender</li> <li>• Compliant with legislation</li> <li>• Patients can ask for doctor of same gender</li> <li>• Staff aware of need for privacy</li> <li>• Space available for private conversations</li> <li>• Privacy of information</li> </ul>	<ul style="list-style-type: none"> <li>• Space for private conversations</li> <li>• Not always able to provide clinician of same gender</li> <li>• Discussions at the bedside can be overheard – curtains are not a sound barrier</li> <li>• Too many visitors at the bedside</li> <li>• Limited single rooms</li> </ul>	<ul style="list-style-type: none"> <li>• Private rooms</li> <li>• Space for private discussion</li> </ul>

**Right 3.4: Children have the right to a dignified death.**



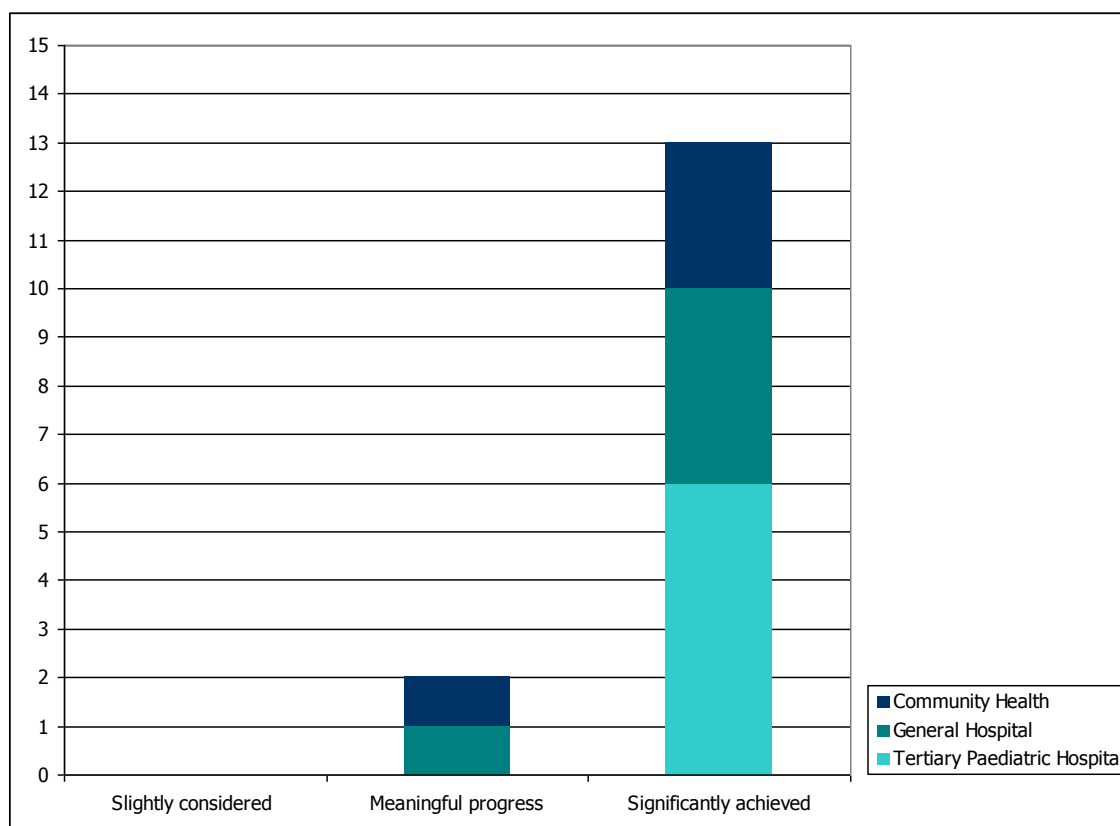
Good Practices	Areas for Improvement	Future Action
<ul style="list-style-type: none"> <li>Palliative care team</li> <li>Palliative care training</li> <li>Support for varied spiritual beliefs</li> <li>Space for families to be with children who are dying</li> <li>Policies/procedures</li> <li>Home palliative care available</li> <li>Child death review process</li> </ul>	<ul style="list-style-type: none"> <li>Space for large families and siblings</li> <li>Training on how to deal with unexpected death</li> <li>Staff education on end of life support</li> <li>Better training in cultural beliefs around death and dying</li> <li>Children have limited access to play and music therapy</li> </ul>	<ul style="list-style-type: none"> <li>Palliative care in nursing curriculum</li> <li>More palliative care training for staff</li> <li>Consumer feedback</li> <li>Review bereavement care</li> </ul>

**Right 3.5: Children have the right not to feel pain.**



Good Practices	Areas for Improvement	Future Actions
<ul style="list-style-type: none"> <li>Pain management protocols/policies</li> <li>Use of pain scores/scales</li> <li>Pain assessment guidelines</li> <li>Training for staff</li> <li>Better access to pain relief for outpatient procedures</li> <li>Children's perceptions of pain recorded</li> <li>Use of child life therapy during painful procedures</li> </ul>	<ul style="list-style-type: none"> <li>Better documentation, scoring</li> <li>Children treated by non-paediatric specialised HCPs</li> <li>No chronic pain service, especially for outpatients</li> <li>Use of pain assessment tools</li> <li>Listening to and understanding the perspective of children and young people</li> <li>Better education</li> <li>After-hours access to pain management service</li> </ul>	<ul style="list-style-type: none"> <li>Dedicated paediatric pain assessment service</li> <li>Staff education</li> </ul>

**Right 3.6: Children have the right not to be submitted to clinical research or experimentation projects and to have the possibility to withdraw during the process of research.**



Good Practices	Areas for Improvement	Future Action
<ul style="list-style-type: none"> <li>• Ethics committee</li> <li>• Adherence to National Health and Medical Research guidelines</li> <li>• Use of information and consent forms</li> <li>• Workshop on ethics and children in research</li> </ul>	<ul style="list-style-type: none"> <li>• Better information for families about their rights</li> <li>• Feedback on research outcomes</li> </ul>	<ul style="list-style-type: none"> <li>• Simpler ethics approval process for quality improvement projects</li> </ul>

### **Overall impact on hospitals of participation in the self-evaluation**

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Participants were asked to report any decisions made to improve the respect of children's rights, in relation to specific rights identified in the self evaluation model and tool, child participation, capacity building and communication, standards and scientific debate and any other areas. Each of the dot points below represents the response from a participating healthcare facility.

#### **Specific rights identified in the Self-evaluation Model and Tool:**

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- *Charter for Children and Young People's Rights to be made available across hospital and community services where children and families attend (concept of 'child friendly corridor'). Area-wide policy on the Rights of Children to be specifically written. Area-wide policy on schooling of children in hospital. Improved data collection and evaluation of health services for children (eg auditing of paediatric ED presentations, impact/outcome of therapeutic interventions). Improvements in Family-centred care can be quantified with regular patient satisfaction surveys. Children should not be admitted with adults in inpatient facility. Designated space for interviewing parents and families when privacy required. All hospital and health service areas that care for children should have child friendly environment and designated play areas (this includes Emergency Departments). More efforts to be made across the board to treat the child as a person and to improve children's participation in decision making*
- *Promote rights that are working effectively*

#### **Child Participation**

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- *Youth Health Surveys.*
- *Yes – Adolescent Inpatient Surveys were run in 2009 & 2010 and will continue.*
- *Establishment of children's forums across the age spectrum is one example of enhancing a voice for children. There are also proposals to ensure that all clinical teams are engaging children in decisions about their care in an age appropriate manner.*

#### **Capacity building and communication**

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- *Our hospital will consider a statement of children's rights as part of our overall family centred care and care system improvements.*

#### **Standards and scientific debate**

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- *Develop area policy "Management of aggression"*
- *Palliative care, communication to children and families, privacy, children not being separated from parents, guardians and caregivers*

#### **Other**

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- *The next step of the process is to review the suggested actions from staff and family members who participated in the evaluation and prioritise a set of projects that will improve children's rights in our health service.*
- *Adolescent ward orientation handout to be developed. Child focused feedback tool to be developed. Establishment of discharge planner role. Guideline for fee waiver for at risk families to be developed. Establishment of local Charter for Children's healthcare. Full*

*implementation of State's Clinical Service Capability Framework for Children's services. Establishment of formalised day stay model of care. Ongoing input of design and model of care of children's services.*

- *This will be discussed at a hospital level to determine the priorities. The self-evaluation will be tabled at our Executive and Hospital wide quality committee.*
- *It should be noted that there are a number of major health reform processes currently being pursued in Australia which will play a part in the plans and future projects relating to the findings of this self-evaluation.*
- *Further development of charter will be achieved with first meeting on consumer participation in one week*
- *In completing this evaluation tool it was evident that a lot of good work was being done in relation to these rights but it was difficult to evidence impact or effectiveness. Our policies/guidelines/general documentation do not speak to these rights in any formal manner. This impacts upon the ability of staff, children and families to advocate for these rights.*

### **General usefulness of the self-assessment**

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The final part of the self-evaluation report asked participants to consider whether the self-evaluation process was useful.

Most participants found the self-evaluation process useful:

- for assessing the respect of children's rights in hospital.
- to plan improvement of hospital activities towards the respect of children's rights in hospital
- in initiating discussion on children's rights in hospital
- in raising awareness about children's rights amongst the health staff, though there were some comments that staff involved in process were already aware of children's rights.

Most could not comment on whether the tool was useful in raising awareness about rights amongst children and young people themselves and their parents/caregivers.

Almost all thought the tool was NOT useful in increasing the participation of children and caregivers in the processes affecting them and there were some comments that it was too soon to tell. Some facilities commented that participation of children and young people and their parents/carers is already a part of the way they operate.

Most participants agreed that a child-friendly version of the self-evaluation tool would be useful, as well as a version aimed at parents and carers.

Some comments or suggestions to improve the tool include:

- A better alignment of the tool used to collect data and the report
- Simplify the formatting of the report
- Expand the self-evaluation to measure other family-centred care practices
- Make the self-evaluation more applicable to non-hospital health care facilities, as the current tool is fairly hospital-centric.



### *Considerations for the future*

The broad consensus amongst all the participating healthcare facilities is that the inaugural self-evaluation process was a very valuable exercise to gauge how well they are considering the rights of children and young people who use their services and for bringing the issue of rights to the surface. There is strong support for self-evaluations to continue, after appropriate review of the process, tools and even the rights themselves.

How the self-evaluation process is implemented in the future will determine how the process and accompanying documentation may change. The question for CHA is whether:

- the self-evaluation will be used as a benchmarking and continuous improvement tool for participating healthcare facilities to measure their ongoing performance in the area of children's rights against other facilities, or
- the self-evaluation is an internal process, whereby healthcare facilities set their own benchmarks and measure progress against themselves.

If it is the former, then it would be appropriate to consider a more rigorous self-evaluation process, which may include peer review of evidence. Participants could be asked to report regularly to CHA which may make the results available to all participants, other CHA member organisations and possibly the general public. CHA is not a regulatory body, so participation in the self-evaluation process would be voluntary. If the latter, then CHA could provide the documentation to hospitals wanting to complete the self-evaluation, but would not necessarily receive their results.

In either case, it may be useful to consider for the future:

- an Australasian version of the self-evaluation (however this may disallow comparisons with healthcare facilities internationally); the current version was developed in Europe.
- using a web-based tool, to help standardise the process and facilitate collation of data
- facilities that had 'significantly achieved' a right be encouraged to share their processes/strategies with others.

There is a push internationally for a review of the self-evaluation model and tool and a strong consensus that additional tools be developed to enable children, young people, parents and carers to participate in the self-evaluation. Also under review is the rating scale and the wording of the rights.

An international working group has been established and revision work has commenced. The ERG will also be considering projects to sponsor in response to the results of the inaugural self-evaluation.

## The Charter

### *Rationale*

The results of the self evaluation survey show that, overall, our health services are committed in principle to respect of children's and young people's rights and demonstrate this commitment in their daily practice. We also found opportunities for improvement, most notably the absence of a Charter of children's and young peoples' rights in healthcare services in Australia and New Zealand, in contrast to the availability and use of such documents in comparable European settings.

A Charter of healthcare rights specific to children and young people is necessary for several reasons including firstly, the fact that they experience illness, injury and disability in a different way from adults, making them particularly susceptible to harm. Secondly, children and young people are vulnerable because of their developmental immaturity. They lack political and economic power within society, including within the health system. Thirdly, children's and young people's level of dependence on the adults around them is constantly evolving along a continuum from dependence to independence. Many people are involved in decision-making for children and young people. Therefore both co-operation and respect between children, young people, families and healthcare professionals are particularly crucial in relation to children's and young people's healthcare.

Further, we contend that children and young people ought to be involved in decision-making about their healthcare to the greatest possible extent, in line with their capacities for understanding and participation. Healthcare providers have an obligation to fulfill their responsibilities to children and young people by providing care that takes into account children's and young people's rights, their evolving capacities, and the rights and responsibilities of parents/carers to provide direction and guidance to children and young people in their care.

### *Process*

CHA convened an ERG of individuals representing CHA member organisations. To strengthen this work, CHA invited the Association for the Wellbeing of Children in Healthcare (AWCH) to be a partner. A sub-committee of the ERG, the Writing Subcommittee, oversaw the development of the Charter.

The Charter is based primarily on: the Australian Charter of Healthcare Rights; the New Zealand Code of Health and Disability Services Consumers' Rights; the United Nations Convention on the Rights of the Child; and, the Charter of the European Association for Children in Hospital.

After appropriate consultation across CHA member organisations, the Australian version of the Charter was launched in November 2010 at the CHA Annual Conference. In continuing to strengthen this work, CHA invited the Paediatric Society of New Zealand to be a partner and the New Zealand version of the Charter is a consensus statement from both these organisations. The New Zealand Charter was launched in May 2011.

Broader consultation on the Australian Charter commenced in 2011 to engage both community and professional stakeholders in progressing and implementing the Charter.

In addition, two rights posters, one designed for children and the other for young people, were developed to complement the Charter. These posters were developed in consultation with children and young people.

### ***Principles of the Charter***

Three general principles underpin the Charter. The first is the primary consideration of the child's or young person's best interests. The second is hearing and taking seriously all children and young people. The third is the recognition that the family is the fundamental group in children's and young people's lives. The family is the environment most conducive to children's and young people's growth and wellbeing and ought to be protected and supported by our healthcare system. All three of these principles should be considered in the interpretation and implementation of all of the other rights.

### ***Breadth of the Charter***

The Charter applies to all children and young people in all healthcare services which they access. It also applies to health promotion and health education activities aimed at children and young people. Healthcare services include (but are not limited to) hospitals, community health centres, general practices and specialists' rooms. The rights are aspirational to the maximum extent of each organisation's available resources. The statement or restatement of a right in the Charter does not diminish that of any other right. A right not included in the Charter must not be taken to be abrogated or limited only because it is not included in the Charter or is only partly included. Children, young people, families and healthcare professionals must be encouraged and supported to speak up whenever these rights are breached.

The specific references to Aboriginal and Torres Strait Islander children and young people in the Australian version of the Charter, and to tamariki and rangatahi in the New Zealand version, are indicative of the fact that these children/tamariki and young people/rangatahi face significant challenges in exercising their rights and that they continue to experience serious disadvantage in their health status. Indigenous children's and young people's rights in healthcare services are the same as for every child and young person, but specific actions are needed to address disparities in access to care. In all contexts in Australia, Aboriginal

and Torres Strait Islander people's self-determination is a vital ingredient for healthcare access and provision. Similarly, in New Zealand it is recognised that Tino Rānngatiratanga (Māori self-determination) is based on te Tiriti Waitangi (The Treaty of Waitangi) right and is also a vital ingredient for their healthcare access and provision.

Some groups of children and young people (such as those in out-of-home care, those with disabilities, those from culturally and linguistically diverse backgrounds, and refugees) may require additional services that address their specific health needs. Particular sensitivity to the backgrounds and abilities of these children and young people will be required in the delivery of these services.

### ***The Rights***

The Charter lists 11 children's and young people's rights in healthcare services as follows:

***Every child and young person has a right to:***

- 1. consideration of their best interests as the primary concern of all involved in his or her care.***
- 2. express their views, and to be heard and taken seriously.***
- 3. the highest attainable standard of healthcare.***
- 4. respect for themselves as a whole person, as well as respect for their family and the family's individual characteristics, beliefs, culture and contexts.***
- 5. be nurtured by their parents and family, and to have family relationships supported by the service in which the child or young person is receiving healthcare.***
- 6. information, in a form that is understandable to them.***
- 7. participate in decision-making and, as appropriate to their capabilities, to make decisions about their care.***
- 8. be kept safe from all forms of harm.***
- 9. have their privacy respected.***
- 10. participate in education, play, creative activities and recreation, even if this is difficult due to their illness or disability.***
- 11. continuity of healthcare, including well-planned care that takes them beyond the paediatric context.***

A New Zealand version of these rights was developed in consultation with the Paediatric Society of New Zealand, children and young people, Manawhenua Ki Waitaha, government and non-government organisations, including the Commissioner for Children and the office of the Health and Disability Commissioner.

***Launch of the Australian version of the Charter***



The Hon Catherine Branson QC (President Australian Human Rights Commission and Human Rights Commissioner) and Prof Les White AM (Chief Paediatrician, New South Wales Health), launched the Australian version of the Charter at the CHA Annual Conference November 2010.



A/Prof Graham Reynolds (CHA President) at the launch of the Australian version of the Charter with representatives from Youth@Kids, the youth advisory council at the Royal Children's Hospital Melbourne.

### *Launch of the New Zealand version of the Charter*

Dr John Angus, Children's Commissioner, New Zealand, launched the New Zealand version of the Charter on 12 May 2011 in Wellington on behalf of CHA and the Paediatric Society of New Zealand.



Dr Paul Watson (ERG) and Elizabeth Chatham (CEO CHA 2008-11)



Dr Richard Aickin (A/General Manager, Auckland City Hospital), Anne Morgan (CHA Board Member) and Mollie Wilson (CEO Paediatric Society of New Zealand)



Dr Rosemary Marks (President Paediatric Society of New Zealand)



Dr John Angus (New Zealand Children's Commissioner to June 2011), Dr Nikki Blair Dr Russell Wills (New Zealand Children's Commissioner from June 2011) and Dr Nicola Austin



## Forum

A Forum on the Rights of Children and Young People in Healthcare services was held on 10 November 2010 during the CHA Annual Conference. Professor Les White chaired the Forum.

**Gillian Calvert, Former NSW Commissioner for Children and Young People**, addressed the topic: *Children and youth health matters*. She emphasised how children and youth concerns can be overlooked in the face of adult concerns and interests. This is as true of health care settings as other settings concerned with children's well being. Ms Calvert's paper outlined how this is played out in health care: in the investment decisions around health expenditure; in the reform of health care systems; in the design and operation of health care settings; and in the practice of individual professionals. Potential strategies for challenging this bias and supporting children and youth rights in health care settings were outlined.

**Dr John Angus, New Zealand Commissioner for Children and Young People** spoke about *Children's rights in New Zealand* starting with a brief overview of children's rights in New Zealand using the UNCRC as a frame of reference. He covered the changes to the Crimes Act to remove the right to correct children by using physical punishment as well as other areas of strengths and weakness in meeting the principles of the best interests of the child, discrimination and participation. Dr Angus highlighted the relatively low priority given to children's interests in government decision-making, the persistence of disparities in generally improving health and education outcomes, and the relative invisibility of children and young people and their views in the public domain. The paper also covered the current legislation and practice around the rights of children to consent to or refuse medical treatment. Angus addressed children's right to confidential treatment, in particular vis-a-vis their parents.

**Loretta Bellato, Youth @ the Kids Facilitator, Royal Children's Hospital (RCH) Melbourne**, described the journey that RCH has been on over the past few years which has led to now formally including patients in the planning and delivery of their services. Among other activities, the RCH has established a Youth Advisory Committee, known as 'Youth At The Kids' or 'Y@K'. Tamara Myors – Y@K Mentor, outlined the context that has driven the RCH to support the inclusion of young people in the planning of RCH services and facilities as well as how this promotes the rights of children and young people accessing hospital services. Members of the Y@K shared what patient and family centered care means for them as patients and siblings of this hospital with a focus on the right they felt to be most important to them as young people, the right to express freely their opinions on any issue that involves them and the right to be heard and to be taken into consideration in a way consistent with their age and maturity (Right 2.2 of the Self-Evaluation Model and Tool).

**Professor Les White**, outlined the Background of Children's Hospitals Australasia CHA's Self Evaluation Exercise and Joyce Murphy, The Children's Hospital at Westmead, NSW presented the collated results. This was followed by a Panel Discussion with Commissioners for Children and Young People moderated by Gillian Calvert, Former NSW Commissioner for Children and Young People, NSW. Panel members were:

- Dr John Angus, New Zealand Commissioner for Children and Young People, NZ
- Megan Scannell, Senior Project Manager, Child Safety Commissioner, VIC
- Paul Mason, Tasmania Commissioner for Children and Young People, TAS
- Kerryn Boland, NSW Children's Guardian, NSW

**Professor Susan Sawyer, Director, Centre for Adolescent Health, Royal Children's Hospital Melbourne**, presented on the topic of Adolescent Friendly Hospitals. She noted that the landscape of contemporary paediatrics has changed dramatically over the last 50 years. Improvements in survival now result in the majority of children with congenital or early onset chronic conditions surviving through adolescence into adulthood. Additionally, the burden of disease in childhood and adolescence has a much greater contribution from developmental, behavioural and emotional disorders than previously. She posed the question: *What implications does this have generally for children's hospitals and for hospitals more widely?* The Royal Children's Hospital, Melbourne has embarked upon a three year project to become a more 'adolescent-friendly' children's hospital. This is based on the notion of Adolescent Friendly Children's Services, a framework promulgated by the World Health Organisation since 2002 in response to the gap between health services sought by young people and the complex health burden they experience. The framework relates to aspects of accessibility, acceptability, appropriateness, equity and effectiveness. In the absence of an appropriate survey tool, 14 indicators of adolescent friendly health care have been identified that will form the basis of a new questionnaire that will be used to survey young people aged 12-18 yrs (880 inpatients, 1200 outpatients) and parents. These results will help guide the priorities for four hospital-wide working parties that are responding to aspects of staff capacity, developmentally appropriate care, adolescent services, consumer engagement and adolescent friendly environments. The commitment to building new children's hospitals suggests wide relevance for this work.

**James McDougall, Director National Children's and Youth Law Centre, University of NSW** spoke on the Non-Government Organisations' (NGO) response to the United Nations Convention on the Rights of the Child in Australia. The NGO Child Rights Report is the Australian NGO sector's Report to the United Nations Committee on the Rights of the Child on Australia's implementation of the Convention on the Rights of the Child. The preparation and presentation of the Report is guided by the Child Rights Taskforce, a coalition of organisations, networks and individuals committed to the development of child rights in



Australia. The Taskforce has begun work on the next NGO Report which will be presented to the United Nations Committee on the Rights of the Child in mid 2011. In July 2009 the Australian Government submitted its own Fourth Report to the Committee. The Government will attend before the Committee to explain its commitment to children in early 2012. The Committee will then release its Concluding Observations on Australia's performance. The Concluding Observations will provide an assessment by the international experts on the Committee that will highlight the positive advances but also draw attention to the areas where the Australian Government needs to improve conditions for children in Australia. Among a broad range of issues, the 2005 Observations drew attention to:

- The systemic disadvantage and discrimination suffered by Indigenous children;
- The need for improved access and coordination in service provision in key areas such as health, child care and education; and
- The lack of genuine participation by children in legal and administrative processes that affect their lives.

### **Recommendations from the project/Future actions**

Having reached agreement on appropriate Charters for both Australia and New Zealand, we now have the responsibility to promote, implement and monitor its effectiveness, in collaboration with key stakeholders.

The following are some suggestions for future action for the ERG.

#### **1. Further work on the Charter**

- a. Develop Version 2 of the Australian Charter incorporating feedback from the broader consultation process including views and opinions of children and young people.
- b. Translate the Charter into other languages.

#### **2. Work relating to implementation of the Charter**

- a. Develop a communication and implementation plan for dissemination and sustainable use of the Charter and posters.

#### **3. Work relating to the Survey Tool**

- a. Repeat the survey in Australian and New Zealand hospitals at a time to be determined.

- b. Improve connections with WHO and HPH and continue representation on WHO working party reviewing the survey tool (Joyce Murphy, Paul Watson, Lauren Andrews, Elizabeth Kepreotes, Virginia Binns)
- c. Promote adaptations of the tool for use in non-hospital settings and non-OECD countries.
- d. Work towards embedding the survey into the EQuIP process. Also consider coalition with other initiatives and organisations interested in the standards of care.
- e. Promote local projects/components, wherein each facility/organisation develops a plan for improvement projects. The role of CHA might be to keep a register of projects and outcomes as well as to provide a vehicle for the sharing of the lessons learnt. Some examples already identified might be:
  - A project focusing on right 2.2, which was the worst rated, was considered to be the most important by the Melbourne youth advisory council.
  - Adults occupying beds in children's wards; separating children and adults on wards and EDs.
  - Lack of child friendly and adolescent areas, play/music therapy and in outpatients, facilities for parents.
  - Child/young person's views not recorded in clinical record; patient and families not always aware of rights.

## Acknowledgments

A contribution from Ronald McDonald House Charities enabled the production and distribution of the publication: *Charter on the Rights of Children and Young People in Healthcare Services in Australia*

## APPENDIX 1: Rights for children: Australian Version

**Let everyone know these are the rights of every child in healthcare:**

1. Know that children are special and always do what is best for us.
2. Listen to us when we tell you how we are thinking and feeling, when we are upset, when we have problems or worries or when we need to talk to you. We may not be able to use words, so take notice of what we do and how we look because this can tell you what we are thinking and feeling.
3. Give us the very best possible care and the comfort we need.
4. Let us and our families be who we want to be, whatever our beliefs and customs, so that we feel safe at all times.
5. Let our families and others who are important to us, be with us to care for us and love us.
6. No matter how big or small we are, tell us what we need to know in a way we can understand.
7. Let us have a say in things that are happening to us now and in the future.
8. No one has the right to harm us, not doctors or nurses and not even our Mums or Dads. Protect us always from anyone who would harm us or treat us badly.
9. Our bodies belong to us. Ask us if you want to share information about us and make sure we stay safe. Give us space and privacy, as well as the chance to be with others.
10. Help us grow up to be the best we can. Let us learn, let us play and discover some things for ourselves.
11. When you care for us, make sure that everyone is working together to do what is best for us, until we are grown up and can decide things for ourselves.

## APPENDIX 2: Rights for children: New Zealand Version

**Let everyone know these are the rights of every child in healthcare:**

1. Know that children are special and always do what is best for us.
2. Listen to us when we tell you how we are thinking and feeling, when we are upset, when we have problems or worries or when we need to talk to you. We may not be able to use words, so take notice of what we do and how we look because this can tell you what we are thinking and feeling.
3. Give us the very best possible care and the comfort we need.
4. Let us and our families/whānau be who we want to be, whatever our beliefs and customs, so that we feel safe at all times.
5. Let our families/whānau and others who are important to us be with us, to care for us and love and aroha us.
6. No matter how big or small we are, tell us what we need to know in a way we can understand.
7. Let us have a say in things that are happening to us now and in the future. Respect our decisions and let us make decisions for ourselves.
8. No one has the right to harm us, not doctors or nurses and not even our mums or dads. Protect us always from anyone who would harm us or treat us badly.
9. Our bodies belong to us. Ask us if you want to share information about us and make sure we stay safe. Give us space and privacy, as well as the chance to be with others.
10. Help us grow up to be the best we can. Let us learn, let us play and discover some things for ourselves.
11. When you care for us make sure that everyone is working together to do what is best for us until we are grown up and can decide things for ourselves.

## APPENDIX 3: Poster for children



## APPENDIX 4: Rights for young people: Australian Version

### Young People's rights in healthcare: "Be in the Know"

Young People's Rights	What this means for you
<b>You have the right to what's best for YOU.</b>	Together with you, everyone involved in your healthcare should always work towards what is best for you. What you value in terms of your physical, spiritual, family and mental well-being is important in deciding what is best for you.
<b>You have the right to express your views respectfully, be HEARD and have something done about it.</b>	You have the right to express yourself and share what you are thinking and feeling with others in any way you are able to communicate. Others around you are responsible for learning how you communicate so your views can be understood. You have the right to have your views heard, considered and taken seriously, especially when decisions are being made that affect you. If you feel like you are not being heard you can choose to have an independent person advocate for you. The right to be heard includes the right to complain about your healthcare. Health services should provide you with a safe and simple way to complain and a fair and speedy way to sort out your complaint.
<b>You have the right to use and receive the BEST available healthcare.</b>	You have the right to the best healthcare available in all situations. The best healthcare available should attend to all aspects of your well-being including physical, spiritual, mental and relationships with family and friends. You also have the right to a safe environment to help you enjoy the highest achievable standard of health. The people caring for you should understand your needs and requirements and try to meet them.
<b>You have the right to be treated with RESPECT in regards to your values, beliefs and culture. You have a right to be you.</b>	You should be treated with respect and dignity and encouraged to respect others' rights and values. You have the right to practice your own culture, customs, language and religion. Whoever you are and whatever your culture, customs, language, or religion you have the right to special protection that makes sure you can practice your ways of life, unless those practices are likely to put you at risk.
<b>You have a right to be with and guided by your FAMILY, unless this is against your best interest.</b>	You have the right to have your parents and those important to you with you, unless this will harm you. You have the right to be given guidance by your parents and family. You have the right to have a support person of your choice with you in any situation you wish, unless this breaks the rights of others or will harm you.
<b>You have the right to be FULLY informed, ask</b>	You have the right to find things out and to be informed. This means having access to information you can understand, trust and that's



<p><b>questions and be given answers about all matters concerning you. Because being in the know is important.</b></p>	<p>important for you to know. This includes:</p> <ul style="list-style-type: none"> <li>• Being given realistic information about your condition and treatment in a way that you can understand</li> <li>• Being able to ask questions and be given honest answers you can understand</li> <li>• Being provided with choices for treatment, where available and realistic</li> <li>• Being aware of how to access information about you if you wish to.</li> </ul>
<p><b>You have the right to be INVOLVED in making decisions that affect you.</b></p>	<p>You have the right to be involved as much as you wish in making decisions that affect you. Depending on the situation, your experience and understanding, and the adults available to support you, you may wish to be informed, to express your views, to have your views taken seriously, to share decision making with parents and healthcare providers or to be the main decision maker. However you wish to be involved, your involvement should be taken seriously. If your views cannot be taken into account, you have the right to be told why.</p> <p>The right to be involved in making decisions includes the right to be involved in making decisions about taking part in teaching or research, and, about the use, return or disposal of any bodily parts or substances removed, changed or added in the course of your healthcare.</p> <p>Healthcare services should enable young people to be involved in decisions about planning services and developing policies that impact on young people.</p>
<p><b>You have the right to be PROTECTED from harm.</b></p>	<p>You have a right to be safe from all forms of harm. This includes being protected from anyone who would harm you including people in your family. Some things that happen to you in healthcare services may be painful but things should always be done to prevent or relieve your pain.</p>
<p><b>You have the right to PRIVACY.</b></p>	<p>You should be treated with dignity. You have the right to a private life, which includes keeping your body, mental, spiritual and social life private. Health professionals should take all necessary steps to ensure your privacy during medical examinations and treatments.</p> <p>Healthcare providers caring for you are aware that your privacy and confidentiality are necessary if you are going to trust them. In some situations, a parent of a young person under 16 years of age will be involved in making decisions about the young person's healthcare and information about them may be shared with a parent. However, your parents do not have an automatic right to information about your healthcare if you do not wish them to. There are some situations in which information about you cannot be shared with your parents without your permission e.g. abortion or contraceptive advice. In other</p>



	<p>situations healthcare providers may have to share information with others to prevent a serious threat to your life or health. Healthcare providers should tell you what information you give to them might be shared with others, including your parents, in order to provide you with the best possible care.</p> <p>You have the right to legal protection from unlawful or unreasonable interference with your privacy.</p>
<b>You have the right to education, rest, play, creative activities and recreation.</b>	<p>Whether you are well, ill or have a disability you have the right to good quality education that helps you develop your personality, talents and abilities to the full. You have the right to rest, play and to be involved in things you enjoy. Sometimes you may not be able to do things you enjoy because they can harm you, especially if you have an injury or illness.</p>
<b>You have the right to planned coordinated healthcare.</b>	<p>You have the right to cooperation among the people providing healthcare to you. This includes having continuity of carers and support, as well as access to ongoing health services as you require them. As you move from children's health services into adult health services, you should be introduced to the new services and health professionals. Your transition from children's to adult services should be made as easy as possible and start early.</p>

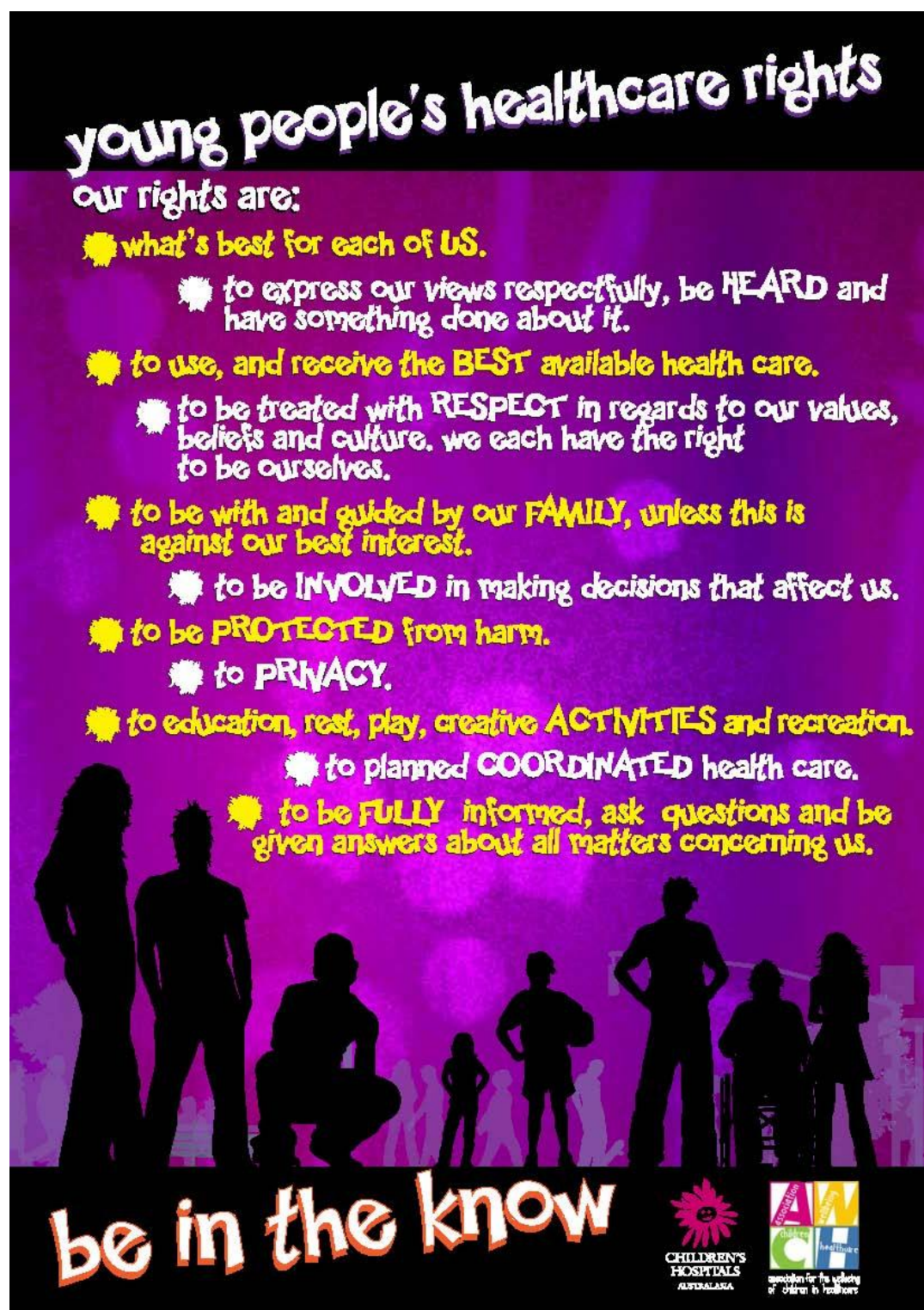
## APPENDIX 5: Rights for young people: New Zealand Version

### Young People's rights in healthcare: "Be in the Know"

Young People's Rights	Details
<b>You have the right to what's best for YOU.</b>	Together with you, everyone involved in your health care should always work towards what is best for you. What you value in terms of your physical (Taha Tinana), spiritual (Taha Wairua), family (Taha Whānau) and mental (Taha Hinengaro) well-being is important in deciding what is best for you.
<b>You have the right to express your views respectfully, be HEARD and have something done about it.</b>	<p>You have the right to express yourself and share what you are thinking and feeling with others in any way you are able to communicate. Others around you are responsible for learning how you communicate so your views can be understood.</p> <p>You have the right to have your views heard, considered and taken seriously, especially when decisions are being made that affect you. If you feel like you are not being heard you can choose to have an independent person advocate for you.</p> <p>The right to be heard includes the right to complain about your health care. Health services should provide you with a safe and simple way to complain and a fair and speedy way to sort out your complaint.</p>
<b>You have the right to use, and receive the BEST available health care.</b>	You have the right to the best health care available in all situations. The best health care available should attend to all aspects of your well-being, including physical (Taha Tinana), spiritual (Taha Wairua), and mental (Taha Hinengaro) and relationships with family/whānau and friends. You also have the right to a safe environment to help you enjoy the highest achievable standard of health. The people caring for you should understand your needs and requirements and try to meet them.
<b>You have the right to be treated with RESPECT in regards to your values, beliefs, tikanga and culture. You have a right to be you.</b>	You should be treated with respect and dignity and encouraged to respect others' rights and values. You have the right to practice your own tikanga, culture, customs, language and religion. Whoever you are and whatever your tikanga, culture, customs, language or religion, you have the right to special protection that makes sure you can practice your ways of life, unless those practices are likely to put you at risk.
<b>You have a right to be</b>	You have the right to have your parents and those important to

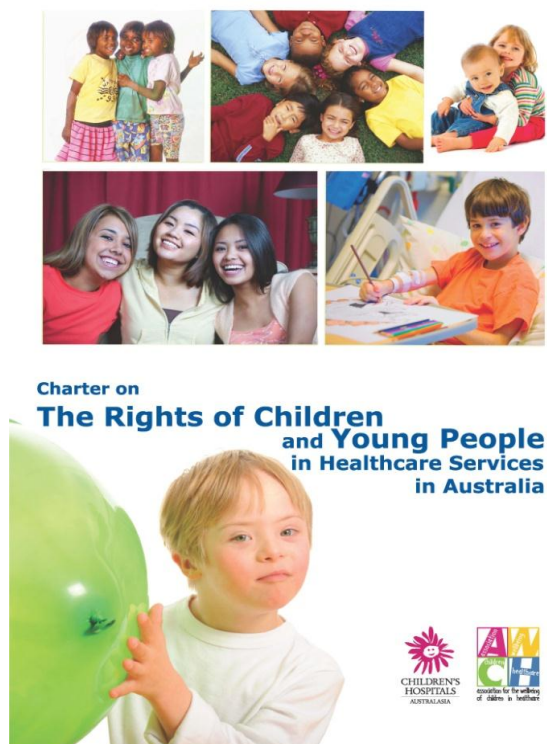
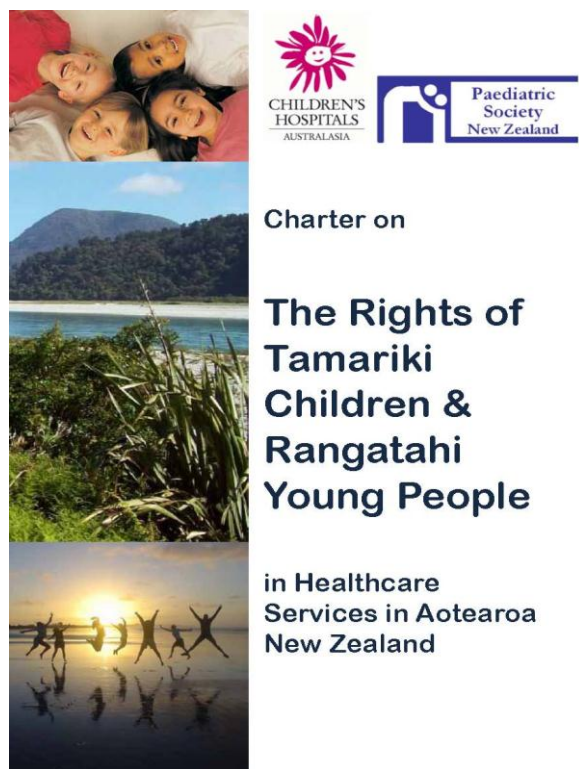
<p><b>with and guided by your FAMILY/WHĀNAU, unless this is against your best interest.</b></p>	<p>you with you, unless this will harm you. You have the right to be given guidance by your parents and family/whānau. You have the right to have a support person of your choice with you in any situation you wish, unless this breaks the rights of others or will harm you.</p>
<p><b>You have the right to be FULLY informed, ask questions and be given answers about all matters concerning you. Because being in the know is important.</b></p>	<p>You have the right to find things out and to be informed. This means having access to information you can understand, trust and that's important for you to know. This includes:</p> <ul style="list-style-type: none"> <li>• Being given realistic information about your condition and treatment in a way that you can understand</li> <li>• Being able to ask questions and be given honest answers you can understand</li> <li>• Being provided with choices for treatment, where available and realistic</li> <li>• Being aware of how to access information about you, if you wish to.</li> </ul>
<p><b>You have the right to be INVOLVED in making decisions that affect you.</b></p>	<p>You have the right to be involved as much as you wish in making decisions that affect you. Depending on the situation, your experience and understanding and the adults available to support you, you may wish to be informed, to express your views, to have your views taken seriously, to share decision making with parents and health professionals or to be the main decision maker. However you wish to be involved, your involvement should be taken seriously. If your views can't be taken into account, you have the right to be told why.</p> <p>The right to be involved in making decision includes the right to be involved in making decisions about taking part in teaching or research and about the use, return or disposal of any bodily parts or substances removed, changed or added in the course of your health care. Health services should enable young people to be involved in decisions about planning services and developing policies that impact on young people.</p>
<p><b>You have the right to be PROTECTED from harm</b></p>	<p>You have a right to be safe from all forms of harm. This includes being protected from anyone who would harm you, including people in your family/whānau. Some things that happen to you in health care services may be painful but things should always be done to prevent or relieve your pain.</p>

<p><b>You have the right to PRIVACY</b></p>	<p>You should be treated with dignity. You have the right to a private life, which includes keeping your body, mental, spiritual and social life private. Health professionals should take all necessary steps to ensure your privacy during medical examinations and treatments.</p> <p>Health professionals caring for you are aware that your privacy and confidentiality are necessary if you are going to trust them. In some situations, a parent of a young person under 16 years of age will be involved in making decisions about the young person's health care and information about them may be shared with a parent. However, your parents do not have an automatic right to information about your health care if you do not wish them to. There are some situations in which information about you cannot be shared with your parents without your permission e.g. abortion or contraceptive advice. In other situations health professionals may have to share information with others to prevent a serious threat to your life or health. Health professionals should tell you what information you give them might be shared with others, including your parents, in order to provide you with the best possible care. You have the right to legal protection from unlawful or unreasonable interference with your privacy.</p>
<p><b>You have the right to education, rest, play, creative activities and recreation</b></p>	<p>Whether you are well, ill or disabled you have the right to good quality education that helps you develop your personality, talents and abilities to the full. You have the right to rest, play and to be involved in things you enjoy. Sometimes you may not be able to do things you enjoy because they can harm you, especially if you have an injury or illness.</p>
<p><b>You have the right to planned coordinated health care</b></p>	<p>You have the right to cooperation among the people providing health care to you. This includes having continuity of carers and support, as well as access to ongoing health services as you require them. As you move from children's health services into adult health services, you should be introduced to the new services and health professionals. Your transition from children's to adult services should be made as easy as possible and start early.</p>





APPENDIX 7: Publications



## APPENDIX 8: Conference presentations/submissions

Elizabeth Chatham. *Rights of the Child*. Council of Children's Nurses Inaugural Conference. Sydney, Australia, 24 - 25 March, 2011. Invited Plenary Speaker.

Haseler S, Chatham E, White L. *The Rights of Children in Maternal, Child and Family Health Services*. Australian Association for Maternal Child and Family Health Nurses Conference (AAMCFHN) 4th Biennial Conference. Gold Coast, Australia, 19 - 21 May 2011 Poster presentation.

Shanti Raman, Joyce Murphy, Les White, Elizabeth Chatham, Patricia Davidson, Karen Zwi, Lauren Andrew, Elizabeth Kepreotes. *Do sick children have rights in Australia and New Zealand? Evaluating compliance with children's rights in Australasian healthcare*. RACP Congress 2011 Darwin, Australia, 22 - 25 May, 2011. Oral presentation.

Elizabeth Chatham, Elizabeth Harnett, Joyce\_Murphy, Paul Watson, Judith Duncan, Lynn Gillam. *Developing an Australian Charter on the Rights of Children and Young People in Healthcare Services*. 19th International Conference on Health Promoting Hospitals and Health Services: Improving health gain orientation in all services: Better cooperation for continuity in care. Turku, Finland, 1 - 3 June 2011. Oral presentation –presented by Virginia Binns.

Murphy J. *Evaluating compliance with the rights of children and young people in Australasian healthcare services*. 19th International Conference on Health Promoting Hospitals and Health Services: Improving health gain orientation in all services: Better cooperation for continuity in care. Turku, Finland, 1 - 3 June 2011. Oral presentation –presented by Virginia Binns.

S Haseler, E Chatham. *Developing a Charter on the Rights of Children and Young People in Healthcare Services* Australian College of Children and Young People's and Family Health Nurses (ACCYPN) Inaugural Conference Sydney, Australia, 19 - 21 October, 2011. Poster presentation. Elizabeth Harnett to present.

Murphy J. *Evaluating compliance with the rights of children and young people in Australasian healthcare services*. Australian College of Children and Young People's and Family Health Nurses (ACCYPN) Inaugural Conference Sydney, Australia, 19 - 21 October, 2011. Oral presentation. Elizabeth Harnett to present.

Les White; Joyce Murphy; Elizabeth Harnett; Paul Watson; Elizabeth Chatham. *Supporting and promoting and the rights of children and young people in health care*. Youth Health 2011. The 8th Australian & New Zealand Adolescent Health Conference. Sydney, Australia, 9 - 11 November, 2011. Submitted for oral presentation.

