



Charter on

The Rights of Tamariki Children & Rangatahi Young People

**in Healthcare
Services in Aotearoa
New Zealand**



Atawhaingia te Pa Harakeke

Nurturing the family

The photo on the cover taken in the Haast Pass (Tiora-patea) includes a Harakeke (flax plant). The flax plant is an image that is used in Māori proverbs to illustrate the importance of tamariki/children and rangatahi/young people to the overall wellbeing of the family/whānau. The central shoot of the flax plant is likened to a child, one either side of the child are its parents, and beyond them are extended family members – all of whom protect the budding child from the ravages of nature.

Charter of Tamariki/Children's and Rangatahi/Young People's Rights in Healthcare Services in Aotearoa New Zealand

**A consensus statement by Children's Hospitals Australasia
(CHA) and the Paediatric Society of New Zealand**



Foreword

In November 1989, the United Nations Conventions on the Rights of the Child (UNCRC) was opened for signature and in April 1993 it was ratified by New Zealand. Eighteen years on we reflect on how far we have come in relation to Children's Rights and where we need to go to, to fulfil our international obligations under the UNCRC.

The UNCRC includes articles that offer reference points to enable development of area specific policy in many aspects of health care for children and young people. An International Taskforce on Health Promotion for Children and Adolescents in and by Hospitals and Health Services commenced work in 2004 developing a Self Evaluation Model and Tool on the respect of Children's Rights. Children's Hospitals Australasia (CHA) has utilised this tool in member's health services in Australia and New Zealand. The Self Evaluation Tool identified health services are doing some things very well, but there is room for improvement.

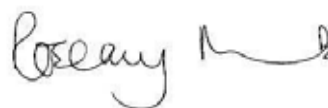
One improvement that was absent in Aotearoa New Zealand was a "Charter of Children's and Young People's Rights in Health Care Services". The development of this Charter is a product of collaboration by members of a CHA Expert Reference Group and writing subcommittee and aligns the rights of children and young people in healthcare services with the UNCRC. We wish to acknowledge the members of the Expert Reference Group: Lauren Andrews, Virginia Binns, Liz Chatham, Anne Cutler, Trish Davidson, Judith Duncan, Lynn Gillam, Elizabeth Harnett, Elizabeth Kepreotes, Bruce Lord, Ros McDougall, Joyce Murphy, Shanti Raman, Stephen Simpson, Paul Watson, Les White and Karen Zwi.

We also acknowledge the excellent work by Judith Duncan, Alison Vogel and Paul Watson in consulting with and drawing together comments from individual and organisational stakeholders across Aotearoa including children, young people, Tangata Whenua and members of the Paediatric Society of New Zealand. We are very appreciative to all those individuals and organisations that so generously provided feedback on earlier drafts of the charter and have contributed to ensuring this charter makes an important statement for children, young people and their families who use health services in Aotearoa New Zealand.

Responsibility for promoting and maintaining the health of children and young people in New Zealand lies with many organisations. Having reached agreement on a uniform charter across New Zealand we have a collective responsibility to promote, implement and monitor its effectiveness. We commend this Charter to all Child Health Professionals and Providers of Child Health Services in New Zealand and ask you to join us in making this commitment to promote, protect and respect the rights of Tamariki/Children and Rangatahi/Young People.



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Background

Children's Hospitals Australasia (CHA) is the widely regarded not-for-profit peak body for children's hospitals and paediatric units in Australasia. CHA's vision is to enhance the health and well-being of children and young people. CHA achieves this by supporting member hospitals to aspire to excellence in the clinical care of children by benchmarking, and sharing knowledge. Membership includes the leading children's hospitals and health services located throughout New Zealand and Australia.

The Paediatric Society of New Zealand is a multidisciplinary organisation of Child Health Professionals from throughout New Zealand. The Society's objectives include promoting the highest standards of clinical practice in paediatrics and child health and advocating for children on all issues related to their health at a local, regional and national level. The Society is pleased to be an active champion in the development, promotion and implementation of a Charter of Rights, designed to focus on the specific health care requirements of all tamariki/children and rangatahi/young people that is appropriate and acceptable to them and their families/whānau.

Early in 2010, the 21st anniversary of the UN Convention on the Rights of the Child, the CHA Board initiated a project on children's rights in health care services. This Charter of Rights and a children and young person's version of the charter forms part of that project. The project is part of a broader initiative undertaken by the Taskforce on Health Promotion for Children and Adolescents in and by Hospitals and Health Services which is a part of the International Health Promoting Hospitals Network, within the World Health Organisation.

The Charter seeks positive approaches in the practical implementation of rights for children and young people in health care services. The Charter has been developed with input from CHA and the Paediatric Society of New Zealand members and their networks. Consultation has occurred with children and young people, Manawhenua Ki Waitaha¹, government and non-government organisations, including the Commissioner for Children, and the office of the Health and Disability Commissioner.

¹A collective of health representatives from the seven Papatipu Runanga in the CDHB catchment who have a memorandum of understanding with the CDHB to assist the CDHB in their responsibilities under the New Zealand Public and Disability Act 2000 and the Ngai Tahu Claims Act 1998

Glossary

‘Aroha’ – Māori term meaning to love, feel pity, feel concern for, feel compassion, empathise, show affection, sympathy, charity, compassion, love and empathy.

‘Best interests’ – the assessment of what is most beneficial to the child or young person, including consideration of the risks involved and the child’s or young person’s own values.

‘Child or young person’ – every human being from birth to the age of eighteen years unless under the law applicable, majority is attained earlier.

‘Cultural safety’ – is the effective health care of a person or family from another culture, and is determined by that person or family. Culture includes but is not restricted to age or generation, gender, sexual orientation, occupation and socioeconomic status, ethnic origin or migrant experience, religious or spiritual belief, and disability (adapted from Nursing Council of New Zealand, 2009).

‘Decision-making’ – any choice to receive treatment, to refuse treatment, or to withdraw consent to treatment.

‘Family’ – the group of people who constitute the child’s or young person’s family is defined by the child or young person and those close to him or her. It is not necessarily limited to blood relatives.

‘Hauora’ – is a Māori philosophy of health and wellbeing.

‘Mana’ – Māori word (noun) meaning: prestige, authority, control, power, influence, status, spiritual power. Mana is a supernatural force in a person, place or object. Mana gives a person the authority to lead, organise, and to make decisions regarding social and political matters.

‘Parent’ – an adult in a primary caring role, including biological parents, adoptive parents, legal guardians, carers and foster parents. Members of the extended family or community may also be involved in the child’s or young person’s care, depending on the family’s circumstances.

‘Privacy’ – protection of body, space, experience and personal identifying information.

‘Rangatahi’ – Māori word for young people.

‘Taha Hinengaro’ – Māori term for mental and emotional well-being including coherent thinking processes, acknowledging and expressing thoughts and feelings and responding constructively.

‘Taha Tinana’ – Māori term for physical well-being including the physical body, its growth, development, and ability to move, and ways of caring for it.

‘Taha Wairua’ – Māori term for spiritual well-being including the values and beliefs that determine the way people live, the search for meaning and purpose in life, and personal identity and self-awareness (For some individuals and communities, spiritual well - being is linked to a particular religion; for others, it is not).

‘Taha Whānau’ – Māori term for social well-being including family relationships, friendships, and other interpersonal relationships; feelings of belonging, compassion, and caring; and social support.

‘Tamariki’ – Māori word for children

‘te Tiriti o Waitangi’ – the Treaty of Waitangi

‘Tikanga’ – refers to customs and tradition, the right way of doing things in Māori culture.

‘Whānau’ – Whānau is a Māori concept that means more than simply an extended family; “a whānau is a diffuse unit, based on a common whakapapa, descent from a shared ancestor, and within which certain responsibilities and obligations are maintained” (Durie, 1994, p. 1). The term whānau has been broadened in more recent times to extend beyond the descent group. In this context the model of whānau, that is the values and obligations which underlie descent-based whānau, are transported into non-descent based groups; “the term whānau is used to express the group members’ commitments to one another and perhaps to a shared purpose” (Ratima et al., 1996, p.7).

‘Whangai’ – Māori word meaning any person adopted in accordance with Māori custom.

Preamble

There are three reasons why a charter of healthcare rights specific to children and young people is necessary. Firstly, children and young people experience illness, injury and disability differently to adults, making them particularly susceptible to harm. They are entitled to special care and support. Secondly, children and young people are vulnerable because of their developmental immaturity. This vulnerability is compounded by the way in which our society is structured. Children and young people lack political and economic power within society, including within the health system. This powerlessness is not an inherent or inevitable consequence of childhood; rather, it can be a consequence of social structures. 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. This is a result of the rapid physical, cognitive, developmental, social and experiential changes which characterise childhood and adolescence.

Many people are involved in decision-making for children and young people. Therefore co-operation and respect amongst children, young people, families/whānau and healthcare professionals are particularly crucial in relation to children's and young people's healthcare. 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 fulfil 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 and guardians to provide direction and guidance to their children.

The charter is a package of eleven rights. Taken together the rights aim to ensure that children and young people receive healthcare that is appropriate and acceptable to them and to their families/whānau. Children, young people and their families/whānau should be able to exercise choice in healthcare services to the greatest extent possible.

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/whānau is the fundamental group in children's and young people's lives. Family/whānau is usually 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.

The charter applies to all children and young people in all healthcare services in which they are treated. 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, they are based on the rights as expressed in the United Nations Convention on the Rights of the Child to which New Zealand is a signatory but they may not represent legal rights in New Zealand law. A right not included in this charter must not be taken to be abrogated or limited only because it is not included in this charter or is only partly included. Children, young people, families/whānau and healthcare professionals must be encouraged and supported to speak up whenever these rights are breached.

The references to tamariki and rangatahi in the charter are indicative of the fact that tamariki and rangatahi face significant challenges in exercising their rights and that they continue to experience serious disadvantage in their health status (Ministry of Health, 2009). Tamariki and rangatahi 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, Tino Rangatiratanga (Māori self-determination) is based on te Tiriti o Waitangi right and is 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) will 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.

Infants and very young children will also require special consideration and services that meet their specific health and developmental needs. These services include provision of support services and information to their parents or carers.

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

Tamariki/Children's and Rangatahi/Young People's rights in healthcare services

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/whānau and the family's/whānau individual characteristics, beliefs, tikanga, culture and contexts.**
- 5. Be nurtured by their parents and family/whānau, and to have family/whānau 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.**

Explanatory notes

1. Every child and young person has a right to consideration of their best interests as the primary concern of all involved in their care.

In this context 'best interests' refers to the child's or young person's overall wellbeing. Well-being (Hauora) is a holistic concept incorporating four equally important and inseparable elements: physical (Taha Tinana), spiritual (Taha Wairua), family (Taha Whānau) and mental (Taha Hinengaro).

The course of action that is in the child's or young person's best interests is the course of action that produces the greatest benefit to that child or young person, taking into account any risks or costs as well. Benefit is in part determined by what is important to the child or young person himself or herself, and so the child's or young person's own tikanga, values and aspirations must contribute to any assessment of what is in his or her best interests.

The child's or young person's own assessment of what would be in their best interests ought to carry great weight, in line with their capacity. The child's or young person's capacity is situation-specific and will depend on his or her experience in the same or similar situations, rather than on his or her age or intelligence. The capacity of children and young people can be enhanced when they are guided and accompanied by parents and extended family or whānau in a manner consistent with their evolving capacities. Friends or other adults who have a close relationship with the child or young person can also offer valuable support. Children and young people have the right to have a person of their choice with them at all times, unless this places at risk their wellbeing or that of another person. The task of assessing a child's or young person's evolving capacity is specific to the particular situation and is best conducted within an ongoing social group of which the child or young person is a part, such as a family or whānau. This could include seeking input from family/whānau members or having family/whānau members present.

Considering the collective cultural rights of the child or young person is part of determining the child's or young person's best interests. However, the best interests of the group cannot be used to justify neglecting or violating the best interests of the child or young person.

In most cases, parents are well-placed to assess what would be in their child's best interests as they know their child most intimately. Healthcare professionals also provide an important perspective on the child's or young person's best interests. Their expertise and experience with many children and young people enable valuable insights. Consequently any assessment of what is in the child's or young person's best interests should be a collaborative process that respects and involves the child or young person, and takes into account the rights and duties of parents and the healthcare professionals responsible for the child's or young person's care.

The consideration of the best interests of the child or young person is both an individual and a collective right. For all policies and programmes that affect them, children and young people should be consulted and given an opportunity to participate in the process of deciding what is in their best interests. Such consultation should include meaningful participation by all children and young people and their families/whānau.

2. Every child and young person has a right to express their views, and to be heard and taken seriously.

Health service providers have an obligation to respect the child's or young person's right to express their view in all matters affecting them. Health service providers also have an obligation to give due weight to this opinion in accordance with the competence of the child or young person. Children and young people may express their views directly or through a representative. To enable children and young people to participate in decision-making processes, healthcare providers need to create an environment based on trust, the capacity to listen, information-sharing and sound guidance.

Health service providers must be attentive to the many bodily ways in which children and young people express their views. Expression begins at birth and can include cries, gestures, posture, verbal communication, changes in physiological parameters and interactions with others, particularly parents. Children's and young people's views may also be expressed through play, art and other activities. Health service providers should attempt to understand and make sense of children's and young people's communications, rather than assume that they do not make sense.

Some children and young people may need or want help to express their views both verbally and non-verbally. Some children will require communication assistive devices in order to meet their right to be heard. The right to be heard includes the right to a representative who will advocate on the child's or young person's behalf in such cases. The right to be heard also includes the right to culturally appropriate interpretation. Further, the right not to express one's opinion is also part of the right to be heard. The right to be heard and taken seriously also applies at a policy level. Children's and young people's views should be sought when making decisions about healthcare in general and to improve their experience of healthcare. This consultation needs to be appropriate and enabling for children and young people; what works for adults is not necessarily the right approach for engaging children and young people.

Children and young people have the right to be empowered to voice any concerns that they have about their healthcare and to have these dealt with appropriately. A child's or young person's complaint should always be investigated and addressed. Children and young people should be encouraged to speak up about their concerns to family members or staff. In some circumstances, a child or young person may need assistance to do this from an advocate. The advocate might be a parent or an independent person. When a child or young person makes a complaint, he or she (not just their family/whānau) should be informed about the investigation and outcome.

3. Every child and young person has a right to the highest attainable standard of healthcare.

Every child and young person is entitled to high quality, safe and expert care. Children's and young people's health services should take a comprehensive approach to the well-being and development of children and young people, addressing the four inseparable and equally important elements of the physical (Taha Tinana), spiritual (Taha Wairua), family (Taha Whānau) and mental (Taha Hinengaro).

Children and young people should be cared for by health professionals whose professional and continuing education prepares them with knowledge and skills related to children's and young people's health, tikanga, culture, development and learning. The physical environment in which children and young people are cared for should be welcoming for children, young people and their families/whānau. The layout, decoration and art works should facilitate children's, young people's and their families/whānau comfort, safety and feelings of control and be appropriate for Aotearoa New Zealand's bicultural society.

Health services should be accessible to children and young people and provide equality of inputs and outcomes without discrimination on the basis of their ethnicity, race, economic status, religion, gender, age, sexual orientation, disability, illness, appearance, language or culture. As much as possible, healthcare should be provided in the home and community. Health services should be planned and administered in co-operation with the communities concerned. When a child or young person is admitted to hospital, this should be as close to home as possible within the bounds of quality and safety, and consistent with good clinical outcomes. Travelling to access healthcare services can involve significant stress and cost for a family/whānau, but is sometimes necessary for the child or young person to receive the best possible care. Children and young people living in cities, regional areas and remote locations are all equally entitled to high quality healthcare that addresses their needs.

Health service providers have a positive duty to ensure that tamariki and rangatahi have equal access to health services. Tamariki and rangatahi are also entitled to specific services aimed at redressing current health inequalities. Employment of Māori healthcare workers and access to traditional healthcare practices should both be encouraged. Health service providers have a duty to ensure information is available in Te Reo Māori and special consideration should be given to providing information in other languages. Special consideration should be given to ensuring that all healthcare services are both developmentally appropriate and culturally safe (Ramsden, 2002).

All healthcare services should encourage optimal nutrition for infants, children and young people. Breastfeeding should be protected, promoted and supported. Extensive resources that are culturally safe and free of charge should be available to help new mothers initiate, establish and maintain breastfeeding. Breastfeeding mothers and their infants and young children should also be supported to continue breastfeeding while the child is in a healthcare service.

4. Every child and young person has a right to respect for themselves as a whole person, as well as respect for their family/whānau and the family's/whānau individual characteristics, beliefs, culture and contexts.

All children, young people and their families/whānau are entitled to respect for their culture, beliefs, tikanga and to culturally safe care. Discrimination against children or young people and their families/whānau on the basis of ethnicity, race, economic status, religion, gender, age, sexual orientation, disability, illness, appearance, language or culture is unacceptable. Healthcare professionals must be sensitive to the values of different cultural groups, and provide services in ways that respect the dignity and mana of each child or young person and

their family/whānau.

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) will 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.

5. Every child and young person has a right to be nurtured by their parents and family/whānau, and to have family/whānau relationships supported by the services in which the child or young person is receiving healthcare.

Every child and young person has the right to be cared for by their parents or legal guardians in a manner consistent with the evolving capacities of the child or young person and with regard to their individual circumstances. Members of the extended family/whānau, whangai or community may also be involved in the child's or young person's care, as provided for by local custom or tikanga. Healthcare organisations and healthcare professionals need to support family/whānau and whangai relationships, and respect the responsibilities of parents and guardians to care for and guide their children and young people. This is achieved by actively facilitating participation by families/whānau in decision-making, planning and the day-to-day care of their child while he or she is in a healthcare service. Parents should be encouraged to stay with their child and offered support and services to facilitate this.

Children and young people are entitled to their parents' and family/whānau members' advice and emotional support when participating in decisions about their healthcare. Close family/whānau relationships mean that parents are often uniquely positioned to provide advice and support to their children. Family/whānau and whangai relationships need to be recognised, encouraged and supported in healthcare services by involving families/whānau in decision making, in a way that reflects and respects the capabilities of the child or young person. Healthcare for children and young people needs to be family/whānau-centred. The provider needs to encourage a parent (or person trusted by the child or young person) to accompany and support the child during procedures when appropriate.

6. Every child and young person has a right to information, in a form that is understandable to them.

Children and young people have a right to information that they can understand about their health and healthcare. This includes information about the choice of health care services available. Special attention and some creativity are often necessary to ensure that children have the freedom to seek, receive and impart information and ideas, not only orally but also through other means of the child's or young person's choice, such as play and art. Ensuring that the language and format used are appropriate to the child's or young person's abilities and level of understanding is essential, as is ensuring that they have understood the information given and had every opportunity to participate

in the conversations about their health and care. This right to information includes the right of tamariki and rangatahi to have access to information in Te Reo Māori and for those from culturally and linguistically diverse backgrounds to have access to information in their own language.

It is crucial that health professionals talk directly to children and young people, as well as to their families/whānau, even if the child or young person may seem unable to comprehend. Health professionals and families/whānau should be as open as possible with children and young people about their health and healthcare. Like all patients, children and young people are entitled to know what is going to happen to them before a procedure occurs and to be given honest information about their condition and treatment outcomes, and to be helped to select and practice strategies for coping.

Giving children and young people timely and accurate information means that they can retain a sense of control about their healthcare, particularly in hospital. Advance preparation for hospitalisation, healthcare procedures or impending surgery provides children and young people with a sense of mastery over the healthcare environment and helps them to cope more effectively with potentially stressful situations.

7. Every child and young person has a right to participate in decision-making and, as appropriate to their capabilities, to make decisions about their care.

Children and young people have a right to be involved in decision-making about their healthcare, to the greatest extent possible in line with their capacities for understanding. The right to be involved in making decisions also includes the right to be involved in decisions about the use, return or disposal of any bodily parts or substances removed, changed or added in the course of health care. Children and young people should be offered healthcare choices wherever possible. Further, they are always entitled to a second opinion. Whenever a child or young person has questions and ideas about their healthcare, these should be heard. If their views cannot be acted on, they are entitled to an explanation.

In order for children and young people to participate in decision-making, the health professionals caring for them ought to be available, trained and committed to communicating with children and young people. Effective communication is critical in healthcare, as children, young people and their families/whānau require appropriate information in order to provide informed consent to treatment. A child or young person needs to be able to talk with the staff caring for him or her, to understand who the staff are and what they do, and to question them about his or her condition and treatment. Participation can include both verbal and nonverbal communication by children and young people with health professionals. It should also include opportunities to communicate through play, art and other media of the child's or young person's choice. Health professionals need to pay attention to ensure that appropriate responses are made to the nonverbal cues and communication by children and young people who use this as their main form (for example, infants, very young children and those with disabilities).

The right to participation extends beyond the right of every individual child and young person to participate in his or her care. It includes encouraging and supporting children and young people as groups to be involved in consultation on the development, implementation and evaluation of the services, policies and strategies that have an impact on them.

Informed consent is to be sought from children, young people and their families/whānau before they are involved in teaching or research. Also, those who do agree to participate must have the opportunity to withdraw at any time without having to give a reason, even if they consent initially. The decision not to participate in teaching or research must not alter access to treatment. Ethical oversight by a Human Research Ethics Committee of all research projects conducted in child healthcare services is part of protecting the children and young people involved.

8. Every child and young person has a right to be kept safe from all forms of harm.

Children and young people are entitled to the highest quality healthcare. They have a right to safe and appropriately expert care, delivered in a child and family/whānau centred organisation and in their own homes. Healthcare organisations should ensure that their staff and physical environments comply with appropriate standards relating to the care of children and young people. This includes providing a developmentally and culturally safe environment.

Children and young people have the right to be protected from abuse, neglect and exposure to family violence. If abuse, neglect or family violence is disclosed, confirmed or suspected health professionals must intervene appropriately in the best interests of the child. Co-operation between healthcare and other agencies, including timely sharing of information, is also essential to ensure children and young people are kept safe and receive safe healthcare.

Taking steps to minimise distress to children and young people in healthcare services is critical. Children and young people also require protection from the potential harm and burden associated with research or teaching (including training of healthcare professionals) while engaged in the healthcare system.

All children and young people, including newborns, are entitled to adequate pain relief. They should be protected from unnecessary pain, investigations, and treatments. They should have access to timely pain management and to services that can address acute (post operative and procedural) pain, persistent and recurrent pain syndromes, and pain during palliative care. When feasible, parents should be supported to hold their child during painful procedures and breastfed infants should be given the option to breastfeed before, during and after painful procedures.

Wellbeing, however, encompasses more than just the absence of physical suffering. Children and young people should be treated kindly, sensitively and in an individually appropriate and culturally safe way at all times. As far as possible, children and young people ought also to be protected from upsetting experiences during their care. If such experiences are unavoidable, the impact should be minimised using all available strategies. Debriefing should be available

for children, young people and their families/whānau if distressing events occur. Seclusion and restraint should be minimal and used only as a last resort.

Children often come to harm during daily activities in their homes and communities. Health services should extend their knowledge and delivery of best practice ways for preventing children and young people from experiencing harm within their homes and community. This includes the provision of accurate and up-to-date information to communities about the ways children and young people are subject to preventable injuries and ways that are effective and available to keep them safe from harm.

9. Every child and young person has a right to have their privacy respected.

The privacy of children and young people must be respected. Privacy is not limited to personal information. A child's or young person's body is an important part of their identity and bodily privacy should be addressed in all aspects of care. This is particularly important in physical examinations and personal hygiene activities such as dressing, toileting and bathing. Children's and young people's religious, cultural beliefs and tikanga may also require special responses in relation to the privacy of their bodies. Children and young people may request a staff member of the same gender and this should be accommodated whenever possible. Healthcare providers should be alert to the fact that children's and young people's wishes around bodily privacy may change as their bodies develop. These wishes should be respected.

The confidentiality of children's and young people's personal information is also important. Proper handling of children's and young people's personal health and other details is necessary to ensure that their information remains private. Keeping children's and young people's details confidential (except where this places them or others at risk), and assuring children and young people that their privacy is important, encourages them to share all of the information relevant to their care with health professionals. Information should not be communicated without the child's or young person's permission, except when he or she is at risk of harm or when the law requires disclosure.

Health service providers should ensure that children and young people have access to appropriate and confidential health advice and counselling without their parents' consent or presence, irrespective of age, where this is needed for the child's or young person's safety or wellbeing. Children and young people may need such access when, for example, they are experiencing abuse at home or are in need of reproductive health education or services. They may also need such advice and counselling in cases of conflict between the child or young person and their parents over access to health services. The right to counselling and advice is distinct from the right to give consent and should not be subject to any age limit.

10. Every child and young person has a right to participate in education, play, creative activities and recreation, even if this is difficult due to their illness or disability.

To the greatest extent practicable, children and young people should be assisted to participate in their regular activities and routines while in a healthcare services. This minimises anxiety and maintains their development and learning. Children and young people ought to remain engaged in education while they are in a healthcare service. They also need an environment in which play and recreation are facilitated, by staff with appropriate knowledge and skills where possible. Play has a particular role in healthcare: it supports the ability of children and young people to cope with their experiences in healthcare services. This requires both a physical environment conducive to play and recreation as well as a commitment across the organisation to giving children and young people the time, encouragement and support to play and participate in therapeutic activities. Opportunities to participate in education, play, creative activities and recreation should be suited to the child's or young person's age and condition. To the greatest extent possible, these activities should take place in an environment designed, furnished, staffed and equipped to meet the child's or young person's needs, interests and abilities.

11. Every child and young person has a right to continuity of healthcare, including well-planned care that takes them beyond the paediatric context.

Healthcare providers need systems to promote continuity of care. This includes care co-ordination both between and within the various services working with children, young people and their families/whānau. Continuity of healthcare between all healthcare services in hospital and community settings is essential. Children and young people who move across different geographical locations and health services are also entitled to continuity of care.

For neonates, children and young people with long term health issues, planning for their care as they develop and move between neonatal, paediatric and adult services is crucial to their wellbeing. Ideally, healthcare professionals should aim for a smooth transition of the neonate, child or young person and their family/whānau to appropriate services. In the context of a transition to adult services this process should begin some years before transfer to adult services is complete. The process of transition should be based on the rights described in this document.

This right to continuity of healthcare also requires health services to adopt a 'whole person' approach, recognising that children's and young people's health and development needs go beyond the health sector. Children and young people need solutions that cross sectors such as health, education, welfare and housing.

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APPENDIX 1: Version for children

Let everyone know these are the rights of every child in health care

- 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 2: Version for young people

Young People's rights in health care: Be in the Know

Young People's Rights	Details
<p>You have the right to what's best for YOU.</p>	<p>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.</p>
<p>You have the right to express your views respectfully, be HEARD and have something done about it.</p>	<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>
<p>You have the right to use, and receive the BEST available health care.</p>	<p>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.</p>
<p>You have the right to be treated with RESPECT in regards to your values, beliefs, tikanga and culture.</p> <p>You have a right to be you.</p>	<p>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 protections that makes sure you can practice your ways of life, unless those practices are likely to put you at risk.</p>

<p>You have a right to be with and guided by your FAMILY / WHĀNAU, unless this is against your best interest.</p>	<p>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/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>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.</p>	<p>You have the right to find thing out and to be informed. This means having access to information you can understand, trust and that’s important for you to know.</p> <p>This includes:</p> <ul style="list-style-type: none"> • Being given realistic information about your condition and treatment in a way that you can understand. • Being able to ask questions and be given honest answers you can understand. • Being provided with choices for treatment, where available and realistic. • Being aware of how to access information about you, if you wish to.
<p>You have the right to be INVOLVED in making decisions that affect you.</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>You have the right to be PROTECTED from harm.</p>	<p>You have the 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>You have the right to PRIVACY.</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 healthcar if you 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>You have the right to education, rest, play, creative acitivities and recreation.</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>You have the right to planned co-ordinated health care.</p>	<p>You have the right to co-operation among the people providing health care to you. This includes having continuity of carers and support, as well as access to ongoing 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>

