

Consent in Child and Youth Health:

Information for Practitioners

Published in December 1998 by the
Ministry of Health
PO Box 5013, Wellington, New Zealand

ISBN 0-478-23500-3 (Book)
ISBN 0-478-23501-1 (Internet)
HP 3254

This document is available on the Ministry of Health's website:
<http://www.moh.govt.nz>



Foreword

The child and youth health community has consistently drawn attention to the need for guidance in the matter of consent. In August 1998 the Ministry of Health convened a workshop, Consent and Child Health. Representatives of the child health community were invited to hear from legal experts and contribute their own issues and ideas.

This publication is a follow-up to the workshop. Its aim is to make information about consent issues and children/young people in health care widely available to child and youth health practitioners of all disciplines. Existing legislation on children's consent to medical treatment is sometimes unclear and some aspects of it are untested in the court. Ethical issues are sometimes complex.

Capacity to consent evolves as the child develops. What is appropriate for one stage may be inappropriate for another. Making a judgement about what is in the best interests of a child involves careful consideration and balancing of a number of rights and needs.

Children and young people live and function within families, whānau and communities. This perspective must be taken into account when health care is provided. Families, whānau and communities can promote (and occasionally inhibit) the development of the child and shape his or her developing identity and independence.

This publication is not intended to be a legal text. Rather, it shares what we know about consent in child and youth health from a legal starting point. It addresses practice questions and attempts to provide solutions which will promote the rights of children and parents to be informed about their children's health care needs and options, and to consent to treatment. It takes into account children's rights to participation and to treatment.

The discussion is kept as simple and sensible as possible and readers are referred to other resources should they wish to follow matters up in more depth. Organisations are encouraged to discuss consent with their staff and develop their own policies.

Pat Tuohy
Chief Advisor
Child and Youth Health

Acknowledgements

The participants at the workshop held in Wellington in August 1998 made a valuable contribution to this publication by sharing their knowledge and experience. The following people have contributed significantly as presenters at the workshop and/or as peer reviewers of the document as it was developed.

Dr Alison Blaiklock, Regional Health Promotion, Auckland Healthcare

John Edwards, Senior Solicitor, Ministry of Health

Annie Fraser, Legal Manager, Office of the Health and Disability Commissioner

Sue Gates, Disabilities consultant

Dr Katherine Hall, Clinical Lecturer, Department of General Practice and Bioethics Centre, University of Otago

Dr Ian Hassall, Child advocate, Children's Agenda

Judge June Johnson, The Family Court

Sarah Kerkin, Executive Officer, Office of the Privacy Commissioner

Robert Ludbrook, Legal consultant

Dr Fiona McCrimmon, Senior Lecturer in Healthcare Law and Ethics, University of Otago

Moe Milne Kaiwhakahaere for the Office of the Health and Disability

Commissioner Chris Parkin, Department of General Practice, Wellington School of Medicine

Ron Paterson, Chief Advisor, Services, Ministry of Health

Nicola Johnson, Sladden Legal consultant

Debbie Sorenson, Chief Advisor, Pacific Health, Ministry of Health

Cynthia Tarrant, Advocate, Office of the Commissioner for Children

Pam Wards, Strategic Services Manager, Community Health, Health Waikato Ltd

Dr Peter Watson, Specialist Adolescent Physician, South Auckland Health

Various Ministry of Health staff advised on the development of this document and assisted in running the workshop. Beth Wood, Policy Analyst, organised the workshop and wrote this document.

The Ministry of Health acknowledges the support of the Health Funding Authority in convening the workshop.

Legal disclaimer

The information in this publication is provided as guidance for practitioners in the child and youth health community. The material should not be taken as an exhaustive statement of the law. If practitioners have specific concerns about cases they should refer to relevant statute and seek independent legal advice.

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Part I: Discussion

1 Introduction

Aim

This publication provides child and youth health practitioners with information about the ethical and legal requirements of consent. It explores issues where there is lack of clarity and provides guidance which may assist in preventing difficult issues arising. It aims to build practitioner confidence and encourage positive and safe practice. This document builds on a workshop held in Wellington in August 1998 and some of the papers from this workshop form part of the appendices. The bibliography provides a range of articles which provide further information and discussion. Discussion is underpinned by acknowledgement of the importance of children's rights and respect for parents, whānau, community and culture.

Issues of consent to health care and authorisation to collect, store and disclose personal information are closely related and some privacy issues are discussed, but readers are referred to the Health Information Privacy Code 1994 for full guidance on the health information privacy rules as they affect health care.

Coverage

There are a range of difficult ethical and consent decisions which may arise in specific cases and these cannot all be addressed globally. For example, the issue of whether or not to recommend treatment for a chronically ill child, when the child and parents do not want this, must be addressed on a case-by-case basis, taking into account the particular condition, family circumstances and beliefs and treatment options.

Some consent issues in child health might be best addressed by legislative change. It is not the purpose of this document to discuss these, and the information supplied falls within legislation and practice as it presently stands. The question of whether procedures like newborn screening of young children should be mandatory because of the likely benefits to the child involves issues of ethics and rights which must be argued within society.

This publication does not address medical interventions affecting the unborn child and the complex issues associated with artificial reproductive technology.

Research in child health is referred to briefly, but it has not been possible to resolve some of the complex legal and ethical questions which have emerged as these will take time to address.

Definitions

Age group

For the purposes of this document the terms 'children' and 'young people' are used to refer to individuals from birth to 18 years, this being consistent with the United Nations

Convention on the Rights of the Child. Some issues discussed are more relevant to one age group than another and therefore sometimes the terms child/children and young person/people are specifically used while the term children/young people refers to the whole age range.

The terms young person/young people refer to people in the age group 12 to 18 years. The terms youth and adolescent are synonymous with the term young person. The information given in this publication is relevant to both children and young people although it is stressed that as the child becomes an adolescent his or her increasing autonomy must be recognised. When a young person reaches 16, for purposes of consent, his or her status is the same as that of any adult.

Health care practitioners

The term ‘health care practitioners’ is used throughout to describe health and disability support service practitioners of all disciplines. It does not refer to medical practitioners alone. Consent is a issue relevant to everyone providing a health and/or disability support service to children in hospitals, pharmacies, clinics, medical centres, homes, schools, marae and in other institutional and community settings.

2 Consent

The values underlying consent

Consent is a fundamental concept in the provision of health care services. It is based on ethical obligations which are, in part, supported by the legal provisions described in this publication. Seeking informed consent is an external expression of a health care practitioner’s pivotal ethical duty to uphold and enhance their patient’s autonomy, by respecting the patient’s personhood in every aspect of their relationship with that individual. Autonomy involves the ability to think, decide and act on one’s own deliberation freely and without coercion even if in the end the person involved decides to let someone else guide him or her.

The value of personhood has different meanings in different cultures. Within Anglo-European culture individual independence is highly valued. Māori, Pacific and some other cultures understand the value of personhood as something realised more completely through collectivity. Therefore, respect for personhood should embrace a range of possibilities and encourage an understanding of consent processes which are similarly comprehensive.

The wellbeing of a person, and their healing if they are ill, are not clinical matters alone. Issues of self-esteem and integrity, or wholeness, are important. Informed consent respects and protects the personal integrity of a patient by affirming the patient’s right to determine what is done to him or her. Personal integrity, like health, has physical, mental, emotional and spiritual aspects.

Ideally the nature of the relationship between a health care practitioner and patient and family is structured in a way that facilitates good outcomes and the patient’s active role in

decision-making. Society's perception of health and disability care givers and its trust in them is enhanced when autonomy and integrity are respected.

The right to authorise or to exert some control over the collection and disclosure of personal information about oneself is a right closely allied to that of consent to treatment and is also relevant to personal integrity and autonomy.

Consent is a process

Consent is not a single act. It is a process involving the individual (and/or their representative if the patient does not have the capacity to consent) being appropriately informed and willing and able to agree to what is being suggested without coercion. It also includes the right to be honestly and openly informed about one's personal health matters. The right to agree to treatment carries with it the right to refuse treatment.

Children and consent

Where children are concerned, consent takes on additional complexity. Not only is childhood a life stage in which capacity is changing and developing, and for which the law is less than explicit in some instances, but there is also a comparative lack of case law on which to base guidance about children's capacity and rights to consent or refuse to give consent to treatment.

In European society children have traditionally been regarded as the property of their parents with little or no personal autonomy. This view began to change towards the end of last century when it was recognised that children sometimes need protection from their parents (and other adults) and that the state had a responsibility to intervene to protect them and promote their development. Children are more vulnerable than adults, although the extreme vulnerability of infants clearly diminishes as children grow up, and they become more experienced and consequently develop the capacity to think and care for themselves.

Children's status – that is, the value and respect accorded them in society, and their access directly and indirectly, to power – has also traditionally been poor and their perceived lack of importance has been reflected in policy and societal attitudes. Respecting children's various capacities and affording them the care and involvement they deserve will contribute to a continual improvement in their status. Informing children appropriately and involving them in decision-making contributes to their development.

Competence and capacity

Within this document 'competence' and 'capacity' are used interchangeably to refer to the ability or capability to make a rational, informed choice about accepting or refusing the treatment or service being offered, or authorising the collection and use of information. 'Competence' is sometimes used to refer to legal 'status', that is, the legal right to consent to treatment on the basis of having reached a certain age.

Regardless of age, an individual must be able to understand:

- that they have a choice (freedom from coercion)
- why they are being offered the ‘treatment’
- what is involved in what they are being offered
- what the probable benefits, risks, side effects, failure rates and alternatives are.

Young people

Although there is no particular age at which any person may be regarded as competent, young people’s increasing maturity and ability to understand complex issues must be recognised and their autonomy respected and promoted. Consent issues for young people differ from those of young children. Where there is a difference of opinion about consent to treatment it will be between the young person themselves and the health care provider rather than their parents and the provider (although the parents may be involved with the young person’s consent).

Information and advice

There are many situations in which children and young people are given health care information and advice, either individually or in a group. The provision of information and advice is not the same as the provision of ‘treatment’ and it is not essential to seek consent from the child/young person and/or their parents to do this. However in most instances it will be desirable to communicate with, and include, parents in programmes and activities involving their children.

3 Children’s rights

The United Nations Convention on the Rights of the Child

This is a very wide-ranging international treaty applying to all children under 18. It was introduced in 1989 and was ratified by New Zealand in 1993. Its provisions have the potential to significantly change our attitudes towards children and they should underpin policy and practice in matters involving and affecting children.

The United Nations Convention sees it as the state’s responsibility (in partnership with parents where they are available and responsible) to ensure that children are:

- adequately provided for in matters of health, education, play, welfare, culture and leisure
- protected from discrimination, abuse, exploitation, injustice and armed conflict
- given a name and identity, are consulted and have their views taken into account, have access to information and freedom of speech and have a right to physical integrity.

While it is in the third area that most change is required if children's participation and status in society is to be increasingly respected, there is clearly a need to balance participation rights and protection rights. These rights are very relevant as we consider consent issues.

Participation and protection

Article 12 of the United Nations Convention on the Rights of the Child requires that all children be assured the right to express their views in all matters which affect them, and that those views be given due weight in accordance with the age and maturity of the child. Article 12 is complemented by provisions contained in Articles 13 (freedom to seek, receive and impart information and ideas of all kinds) and 17 (assuring access to appropriate information).

Article 3 requires that, in all actions concerning children, the best interests of the child shall be the primary consideration. This places some responsibility for decision-making concerning the welfare of children with adults.

Although this is not incompatible with the provisions of Articles 12 and 13, caution must be observed to ensure that the best interests principle is not indiscriminately used to override the wishes and interests of children. These can be best protected by ensuring that children are well informed to the level of their understanding and in ways which enhance that understanding, and that they are listened to and have their views taken seriously.

The most recent legislation affecting rights to consent in health issues, the Code of Health and Disability Services Consumers' Rights, does not single children out at any age as having different rights from any other consumer, and presumes that every consumer is competent unless there are reasonable grounds for believing otherwise. This is consistent with an approach that emphasises self-determination to the fullest possible extent. Where self-determination is not possible, consideration is afforded the best interests of the child.

Article 24 of the United Nations Convention on the Rights of the Child recognises the right of the child to the enjoyment of the highest attainable standard of health, and to facilities for the treatment of illness and rehabilitation of health, and states are required to ensure that no child is deprived of his or her right of access to health care services. Clearly this article should also guide how we approach matters of consent. It means that the ways in which we seek the consent of children and/or parents and families/whānau, or make decisions about the treatment of a child, should enhance and not inhibit the child's opportunity to get the best health care available for their particular circumstance.

Responsibility to give advice

Child health practitioners have a responsibility to give the children/young people, and parents involved in any decision, clear and understandable information. Because practitioners have expertise that other parties may not have, they should also give clear advice as to which course of action will lead to the highest attainable standard of health.

Because younger children are less developmentally mature than adults, any information and advice must be given in language suitable for their age and level of comprehension. If a parent and child are spoken to together it cannot be assumed that the child will understand advice and information given to the parent, or that the parent can be relied upon to pass the information and advice on in a way that the child will understand.

Treaty-based rights

The implications of the Treaty of Waitangi in a health care context mean that tamariki Māori have the rights to the same health outcomes as children of other ethnic groups. Because issues of culture and identity impact on the determinants of the health and wellbeing of tamariki Māori, practitioners are obliged to recognise these factors as relevant when issues of consent to health care of tamariki Māori arise.

4 Families, whānau, communities and culture

Respecting the rights of children and young people as individuals is clearly very important in influencing the ways we view them and behave with them. However, children and young people do not exist in isolation. They live and develop inside complex contextual environments. Children's developing sense of identity and uniqueness is intricately bound up with the dependent and interdependent relationships they have with their parents, wider family, whānau and important aspects of their community, in particular their cultural and religious heritage. It is therefore unrealistic and unhelpful to consider consent issues without taking these factors into account and acknowledging the sometimes conflicting needs and rights of important people involved in a child's life.

In thinking about the best interests of a child it is relatively easy to acknowledge these factors as part of a holistic view of the child's health; it is much harder to place relative weights on such factors when facing life-and-death decisions, or when struggling with doubts about the personal agendas (for example, matters of power and ownership) of the adults involved.

The place of tamariki in Māori whānau

The term whānau has a number of meanings all of which possess a common thread or function: that of collectivity and a sense of belonging and sharing a common whakapapa (ancestry). 'Whānau' may be used to refer to a set of siblings descended from common parents or to an extended group of relatives with a common recent ancestor, or to descent groups of much greater genealogical depth. Today it may also mean a group that is not clearly based on common descent but is made up of kin related in a variety of ways who have common interests. It is also sometimes used for an ad hoc group working together to support a common cause or person.

Traditionally tamariki (children) have a very special place in a whānau. Tamariki are regarded as very special, as gifts or taonga (treasures) and as belonging to the whānau in a broad sense of the word. They belong not only to mātua (parents) but to kaumātua and kuia (grandparents) and tīpuna (ancestors). The whānau has a collective responsibility for their care. A child is part of a whānau, hapū (extended family) and iwi (tribe) and is a taonga to

all these groups. Mātauranga, or important cultural knowledge, is passed to succeeding generations through tamariki. Tamariki are the repository of te reo Māori (language). The child also belongs to the whenua (land) and is part of the environment.

Because a child is not regarded as belonging to one or both parents, responsibility for decision-making is shared with significant and available members of the whānau. When it comes to seeking consent this means that, wherever possible, decisions about a child may involve whānau as well as the immediate parents and the child. Policies should ensure that tamariki and whānau are supported in ways that facilitate this happening. This involves changing from thinking about a child's rights in purely individual terms to more collective terms. In practice, many children and families in all ethnic groups have extended family networks available and determined to support and assist in decision-making when opportunities are made for inclusion.

Pacific children

Pacific families in New Zealand are a diverse group coming from 22 countries. Even within groups from the same country of origin, Pacific people may differ depending on whether they were born in New Zealand, their use of the English language and their involvement in church or sporting groups. Nevertheless, Pacific people share some common factors and attitudes relevant to the topic of consent and child health. Pacific people have a high proportion of children within their population, and these children experience poorer health than most New Zealand children; 20% percent of Pacific people in New Zealand do not speak English fluently; the extended family is the foundation of their community.

Pacific children are viewed as part of an extended family and community. The wellbeing of an individual is contingent on their integration with their family and community as a whole, and on the community's overall wellbeing. The spoken word is the usual mode of communication. Nevertheless, because of traditional respect for authority, Pacific people might not admit they do not understand and might not ask for additional information when unclear about something.

Traditionally, decisions are made by an extended family group or community and an issue is discussed until it is resolved, perhaps by intervention from the 'right' person. Older people are regarded with respect and their views are influential, as are community leaders such as church ministers.

Practitioners can facilitate decision-making by:

- supporting children and parents to include wider family and community groups who can provide support and assist in decision-making
- allowing appropriate time for decision-making when this is safe
- understanding the importance of the extended family, and the church
- ensuring that children and families are fully informed in a manner they understand.

Pacific people should also be offered opportunities to ask questions in a way that respects the processes common to most Pacific groups.

5 Communicating with children/young people and families

Involving the whole family

Children and young people live and grow in families and whānau, members of which, in most cases, love and care for them. Therefore it is important to ensure that consent involves not only the child (if they are mature enough) but other important members of that family. The wishes of the child and family are a good guide to whom to involve.

Occasionally, situations arise where there are disagreements about consent to health care procedures: between parents and young people, between parents and practitioners or between family members. Wherever possible, families should be given the time, information and supportive resources (extended-family members, elders, church ministers or professional counsellors and social workers) to work these differences through. Where health outcomes for children/young people are seriously impaired by refusal of any entitled party to give consent, legal advice should be sought.

In some health care situations children/young people and families will be anxious and stressed. These factors can affect the ability of children/young people and parents to listen, understand and remember what is explained to them. This must be taken into account when information is provided. Children's ability to understand what is being explained will depend not only on their physical and emotional state at the time but also on their developmental and emotional maturity. The extent of the information provided and the degree of complexity communicated must be tailored to the child's ability to understand.

Promoting understanding

Information may need to be given more than once and in more than one form. In addition to verbal explanations it is useful to have available a variety of written information suitable for different ages and in different languages. Some people will find written or diagrammatic information a way of accessing and understanding their options. In every case the written information needs to be simple, clear and concise, and needs to address the questions the parent or child may ask. Pamphlets, posters, charts and diagrams may be appropriate visual aids to communication in various circumstances. With children, the use of toys and simple, relevant story books can help understanding.

Practitioners should consider who is available to give information to a child and their family and, where possible, use staff with appropriate interpersonal skills and of an appropriate culture. Many hospitals and health services have Māori and Pacific staff, play specialists, trained paediatric nurses and social workers who may be available to assist practitioners in imparting information in an appropriate way, and in encouraging parents and children to ask questions.

Time and timing

The busy nature of most health care settings imposes problems of time and timing which can interfere with the processes important to gaining informed consent. Where possible, procedures should allow enough time to impart information to children, young people and families, so that they can understand and come to terms with information before they are asked to consent to a procedure. When clinical events (for example, immunisations and blood tests for new-born screening) are routinely anticipated, staff caring for someone whose consent is required should prepare the person, in the most appropriate manner, well ahead of the event.

Some health care interventions are delivered in emergency situations, or when children and/or parents are too unwell to fully comprehend and adequately respond to requests for consent. Such situations must be responded to on a case-by-case basis, remembering that in emergency situations necessary to save life or prevent serious damage to health consent can be dispensed with. In many situations there will be an alternative family member available to give consent and this must be actively sought. When, in an urgent situation, action is taken without consent, making time later for an informing and debriefing process will make the patient and their family feel that their rights have been respected.

The support of parents

Parents are very protective of their children, may be anxious to protect them from additional fear and be reluctant to have information about a child's condition or treatment shared with the child. In general, honest and clear information given in an age-appropriate and supportive fashion reduces fear. However, it is wise to seek parental support before giving a young child information. In examining or assessing a young child, a practitioner will want to explain what they are doing and why and to seek the child's co-operation and implied consent in an informal way. The degree to which parents are involved in decision-making will vary on a case-by-case basis depending on the age of the child, the complexity of the planned intervention and the wishes of a mature child. In practice parents will be very involved in most situations.

A frightened child

Some health care settings and examination and treatment procedures can be frightening for people of all ages. A frightened, upset individual who is unwell and/or in pain will not always be co-operative or agree to what is going on. In such situations their capacity to give informed consent may be impaired. While every effort must be made to help young children feel safe and explain what is going to happen, and to allow them time to accept what is going to happen, their parent's consent to their treatment will be sufficient to proceed if for health reasons treatment should not be postponed.

Young people

Young people must be given the opportunity to be heard in their own right and to have their opinions valued. While the degree of maturity and ability to communicate with confidence varies from individual to individual, demonstrating respect for their increasing autonomy will assist a young person's ability to express his or her views. For some young

people the support of friends and peers is very important. It may be appropriate to ask the young person (and their family if the young person agrees) if he or she would like the chance to talk the issue over with his or her friends or people of similar age.

6 Summary: Consent in practice

Fundamental elements

- The function of consent in the health context is to protect an individual's rights to bodily integrity and autonomy by allowing that person to determine what is done to him or her.
- Consent must be freely given, informed and given by a person who is competent to do so.
- Children/young people should be informed and involved in decisions affecting themselves at a level appropriate to their maturity and understanding, regardless of their capacity to consent.

While there is some lack of clarity about the capacity and legal entitlement of children and young people under 16 to consent to treatment (without parental consent), good practice can compensate for uncertainties.

Principles underlying effective management of consent in child health

- The best interests of the child/young person and their health and welfare should be the primary considerations subject to the rights of parents and children to express their views and have those views given due weight.
- Effective communication (clear, age-appropriate information and advice given at the right time, in the right place by the right person/s) is the key to avoiding most consent problems.
- Respect the child/young person as an individual, offer them the degree of participation they are mature enough to cope with and consider them within the context of their family and culture.
- Ensure that all staff are well informed and guided by policies that comply with legislation and support good practice.

Part II: Questions and Answers

This section is complemented by Part III which gives more detailed information on relevant legislation and some further practice guidance.

At what age can a child/young person give consent to health care?

- (a) Under the Guardianship Act 1968 young people over 16 can consent to health care procedures. As with any adult, a health care practitioner can overturn this right if there are reasonable grounds for believing that a person is not competent.
- (b) Children and young people under 16 years can consent to their own medical treatment in the cases of:
 - abortion where parental consent is not required, whatever the age of the child (s. 25A Guardianship Act 1968)
 - contraceptive advice and treatment (repeal of s. 3 of the Contraception, Sterilisation and Abortion Act 1977).
- (c) There are some explicit situations in which parental and/or child consent is not required:
 - abortion (see above)
 - administration of blood transfusion in certain circumstances (s. 126B Health Act 1956)
 - the examination of children (on a court order) on suspicion of child abuse or neglect (s. 49 Children, Young Persons and Their Families Act 1989); the child is entitled to have an adult present during the examination (s. 54)
 - where guardianship of the child has been vested in the court and the power to give or withhold consent rests with the court or its agent (ss. 10A–10E Guardianship Act 1968)
 - where the Director-General of Social Welfare has been appointed sole guardian of the child, consent can only be given by the Director-General (s. 110(2)(a) Children Young Persons and Their Families Act 1989); but note that a child aged 14 or over can apply to the Court to overturn a refusal of consent by the Director-General in respect of any important matter which affects the child (s. 116)
 - examination of children in school and early childhood education services by persons authorised under s. 125 of the Health Act 1956.

In other circumstances health practitioners appear to have presumed an obligation to obtain parental consent if a child is under 16. This is because the Guardianship Act does not explicitly permit children under 16 to consent to their own health care. However, the

presumption that parental consent is necessary in order to give health care to children and young people under 16 is inconsistent with common law developments and the Code of Health and Disability Services Consumers' Rights 1996, a regulation under the Health and Disability Commissioner Act 1994.

Is it necessary in other situations to get the consent of a parent?

In the situations given in (a), (b) and (c) above, the position is regulated by specific New Zealand statutory provisions. In all other situations the legal position is governed by the Code of Health and Disability Services Consumers' Rights and common law. The common law rule as to the ability of children under 16 to give an effective consent to medical treatment received careful consideration by the House of Lords in 1985. In *Gillick v West Norfolk and Wisbech AHA*, the Court decided that whether or not a child can give an effective consent to medical treatment depends on the child's individual capacity to make an informed decision. The decision is generally accepted as binding for New Zealand courts.

The *Gillick* decision rests on the principle that children are individuals who grow in intelligence, competence and autonomy as they move towards adulthood. Before providing medical treatment for someone under the age of 16, the practitioner must determine whether the child has the understanding and maturity to form a balanced judgement about the proposed treatment. If so, the child can be treated without obtaining parental consent; if not, parental consent must be secured before treatment is given.

The Court in *Gillick* did stress that practitioners should make every effort to encourage the child to involve his or her parents, in any medical decision. But if the child refuses to involve the parents, or if the parents refuse to give consent, the doctor can proceed to treat the child if satisfied that the treatment is in the child's best interests and provided the practitioner is satisfied that the child/young person has the understanding and maturity to make the decision. The practitioner's judgement as to the child's level of maturity and understanding should be based on the individual characteristics of the child, not on some rule of thumb or fixed chronological age.

The *Gillick* test recognises that parental control over children diminishes as the children grow in intellectual capacity and maturity and that young people, as they move towards adulthood, are able to make more and more important decisions for themselves.

The *Gillick* test is reflected in the Code of Health and Disability Services Consumers' Rights which creates a presumption of competence (right 7(2)) and recognises the right of a consumer with diminished competence to retain the right of informed consent to a level appropriate to his/her competence having regard to the nature of the procedure (7(3)).

The Code's presumption of competence, the common law and our increased recognition of children's participation rights (endorsed by the UN Convention on the Rights of the Child) provide clear support for seeking children's consent to their health care and for providing them with information about matters affecting them.

However it is good practice to seek the consent of parents and their competent children to health care procedures. In most cases this will be what children want given the positive

nature of most family situations and a child's need for guidance and support. This approach respects children's participation rights, parents' natural wish to be part of decisions affecting their children, and cultural practices.

What if a child/young person and parents disagree?

The key to managing this situation will be providing the child/young person and their parents with sufficient opportunity to work their differences through, separately or together, depending on the circumstances of the case. The health service involved may be able to assist by providing social work, counselling or cultural support and assistance to family members. In some situations it may be advisable to seek an independent 'advocate' to represent the views and/or interests of the child/young person.

Factors affecting decisions will vary on a case-by-case basis depending on the urgency for treatment, the age of the child/young person and the nature of family relationships. Only when matters cannot be resolved informally should it be necessary to seek legal advice.

What if a child/young person seeks treatment themselves (other than for contraception and abortion) and asks that their parent/s not be informed?

This situation must be judged on a case-by-case basis, and where it is clearly appropriate (in terms of the individual's safety and support needs) the practitioner should discuss the matter with the child/young person and encourage (not coerce) the child/young person to involve their parents. In some situations it may be important for the practitioner to disclose the child's condition to others in order to keep the child safe (suicide attempt or child abuse, for example).

Although the situation has not been tested in court, it is likely that the child/young person's treatment and consent rights under the Code of Health and Disability Services Consumers' Rights and common law and their privacy rights under the Health Information Privacy Code enable them to be advised and treated without their parents being involved.

Sometimes a practitioner will have the role of encouraging parents to accept the value of their young person's autonomy and independent relationship with their health practitioner.

Can a child/young person refuse health care?

Young people over 16, if they are competent, can refuse treatment and their refusal cannot be overruled by their parents.

The Bill of Rights Act 1990, the *Gillick* decision and the Code of Health and Disability Services Consumers' Rights all support the view that children under 16 can effectively refuse medical treatment, certainly where they are of sufficient maturity and understanding to weigh the implications. Some experts argue that because the Guardianship Act gives children aged 16 or over the right to consent to medical treatment, by implication younger children cannot give effective consent and that the same argument would hold for refusing treatment. Court of Appeal decisions in England suggest that parents can give consent on

behalf of their children even where the children have the capacity under the *Gillick* test. The issue has not been decided by the New Zealand courts.

Children often resist treatment because they are distraught and fearful and because some treatments are uncomfortable. Good explanation and support will reduce the chance of children protesting against their treatment. The fact that the child is unwell, frightened and distraught does not mean that the he or she necessarily lacks the competence to give an effective consent, but these factors may be indicators that the child lacks mature understanding of the implications of having or refusing treatment. The practitioner will have to make a judgement about the child's capacity. Where:

- there is no alternative viable treatment that distresses the child less
- administration of treatment is regarded as being in the child's best interests
- the consent of parents or other legally entitled person has been obtained

the practitioner may proceed.

Where no one legally entitled to consent is available, steps set out in right 7(4) of the Code of Health and Disability Services Consumers' Rights must be followed.

How is capacity to give consent assessed?

This too must be considered on a case-by-case basis, taking into account not only the age of the child, but their functional maturity, the complexity of the information being given, the seriousness of their medical condition and the implications for the child of treatment and nontreatment.

It is not acceptable to assume that children (or children/young people with disabilities) are automatically incompetent. Children should be assumed competent unless assessed otherwise. Determining competencies is a process that is situation - and treatment-specific. Ability to give consent must be assessed for each situation.

The following questions may help a practitioner to assess the individual's competence:

- Does the patient understand why they need the intervention?
- Does the patient understand what the intervention involves and what it is for?
- Does the patient understand the probable benefits and risks and what the alternatives are?

If a child does not have the capacity to consent, who can consent for them?

If a child is not capable of giving consent, then it will be necessary for the practitioner to obtain the consent of a parent or legal guardian of the child. If the child is under the guardianship of the Director-General of Social Welfare or of the Court, their consent must be secured before treatment is given.

The same is true in regard to matters of collection of information under the Privacy Act 1993. Rule 3 of the Health Information Privacy Code says that where a child could not be expected to fully understand an explanation, an explanation should be made at the child's level to the child, and a full explanation given to their representative. Similar requirements apply to people with mental or intellectual disability.

Further, under the Code of Health and Disability Services Consumers' Rights those entitled to consent on behalf of the child are included in the definition of 'consumer' and are entitled to all the information necessary to make an informed choice or give informed consent.

In circumstances where there are conflicting parental views, the consent of one parent is enough to proceed with medical treatment. The Guardianship Act refers only to the consent of *a* legal guardian. However, health care practitioners are placed in a difficult position when legal guardians (parents in particular) do not agree. If the situation cannot be resolved through discussion and counselling, practitioners should seek legal advice. Section 13 of the Guardianship Act 1968 makes provision for the Court to make an order on a matter affecting the welfare of a child when there are disputes between people who together have guardianship or custody of a child.

In what circumstances is consent not necessary?

- (a) In emergencies, where an appropriate person cannot be found to give consent, health care professionals can – and have an obligation to – provide relevant treatment (common law and Crimes Act 1961).
- (b) Blood transfusions can be administered to children without consent in certain circumstances (s. 126B Health Act 1956).
- (c) Some legislation allows for compulsory treatment, for example the Mental Health (Compulsory Assessment and Treatment) Act 1992. The Health Act 1956 and the Tuberculosis Act 1994 also contain provisions for compulsory examinations and treatment.
- (d) In situations where a person of any age (including children and young people) is suspected of having excess blood alcohol levels, blood specimens may be taken by a registered medical practitioner or 'authorised person' without consent if required by an 'enforcement officer' (Transport Act 1962).

What if parents refuse to give consent in life-threatening circumstances?

Parents sometimes refuse to give consent to medical treatment in life-or-death situations because of strongly-held religious, cultural or quality of life beliefs. In some circumstances, involving the appropriate people in discussion with the family (for example, extended-family members or elders from their community), providing full information and allowing time for issues to be worked through may lead to satisfactory

resolution of the problem. If there is an adequate alternative treatment available that does not offend the parents' cultural or religious beliefs, it should be used.

In situations that do not resolve, practitioners should be guided by the best interests of the child and their right to life and make application for intervention by a Court. Legal assistance will be required to do this.

Parents have the right to refuse consent in respect of any child who lacks the capacity to give a consent. The only way in which such parental refusal can be challenged is through an application for a declaration that the child is in need of care and protection (ss. 14 and 67 Children, Young Persons and their Families Act 1989), or an application to place the child under the guardianship of the Court (s. 10 Guardianship Act 1968).

In New Zealand there have been a number of court decisions made in favour of treatment when cultural and religious beliefs have led to parents refusing to give consent (see R Paterson 'Legal and Ethical Dilemmas', Appendix 2). Quality of life decisions are more complex and are likely to depend on both clinical issues and on broader issues relating to the child's wellbeing and quality of life within his or her family.

How should consent be obtained for routine health care?

Immunisation, new-born screening and dental treatment are examples of situations in which parents may not give consent to medical intervention where relatively safe procedures have the potential to improve or protect health for children. In these cases consent may have been sought but simply not followed up on by parents who do not respond to a written request.

The key to obtaining consent is high-quality practice. Essential components include:

- timing the provision of information so that last-minute decisions do not have to be made
- not relying entirely on written information – some parents will need to talk the issues through with someone they are comfortable with
- making the process of giving consent as simple as possible with minimal paperwork involved
- having the capacity to follow up situations where a parent has refused consent or failed to respond to a request for consent
- avoiding pressure or coercion of parents – consent must be freely given
- having culturally effective practitioners available
- ensuring that in every case the provider caring for the parent and/or child identifies a particular practitioner responsible for seeking consent.

How informed is ‘informed’? How much information should be given to parents and children?

This, too, is a matter which must be judged on a case-by-case basis depending on the complexity of technical matters and the age and understanding of the individual from whom consent is sought.

The Code of Health and Disability Services Consumers’ Rights gives some guidance. Right 6(2) provides that before making a choice or giving consent, every consumer has the right to information that a reasonable consumer, in that consumer’s circumstances, needs in order to make an informed choice or give informed consent.

Furthermore right 6(1) indicates the type of information that should be provided regardless of whether a particular choice is being made or consent is being given:

Every consumer has the right to the information that a reasonable consumer, in that consumer’s circumstances, would expect to receive, including:

- (a) an explanation of his or her condition*
- (b) an explanation of the options available, including an assessment of expected risks, side effects, benefits, and costs of each option*
- (c) advice of the estimated time within which the services will be provided*
- (d) notification of any proposed participation in teaching or research, including whether the research requires and has ethical approval*
- (e) any other information required by legal, professional, ethical, and other relevant standards*
- (f) the results of tests*
- (g) the results of procedures.*

Right 6(3) provides that consumers are also entitled to honest and accurate answers to questions about services and, on request, a written summary of the information provided.

Where a child is not competent to consent, he or she must still be provided with information appropriate to his or her level of understanding, in addition to information given to the person from whom consent is sought.

There is a risk that practitioners will allow some practices to get in the way of obtaining consent, for example, they may rely too much on form filling and other paperwork. Advice giving should not be confused with coercion. Practitioners are obliged to provide a recommendation if requested.

Does consent have to be in writing?

In many circumstances, following the correct process of obtaining consent is much more important than obtaining written consent. It is therefore more important that the parents and/or children/young people are well informed, have the capacity to give consent and do so freely.

Where consent is obtained formally but not in writing it is good practice to record what was discussed, when the discussion took place, and that consent was obtained.

Written consent is not essential except in circumstances where it is required in law for example, the Mental Health (Compulsory Assessment and Treatment Act) 1992 requires that written consent be given to treatment after the first month of treatment (s. 59), and to electroconvulsive treatment (s. 60) and brain surgery (s. 61).

The Code of Health and Disability Services Consumers' Rights requires consent to a health care procedure to be made in writing if:

- the consumer is to participate in any research; or
- the procedure is experimental; or
- the consumer will be under general anaesthetic; or
- there is significant risk of adverse effects to the consumer.

What are the possible consequences for health care practitioners who fail to comply with consent requirements?

Unless there are specific legal exceptions to the need for consent, the health care practitioner who acts without consent potentially faces the prospect of a civil claim for exemplary damages, criminal prosecution for assault (s. 196 and s. 190 Crimes Act 1961), complaint to the Health and Disability Commissioner and professional discipline.

On the other hand, in emergency life-and-death situations health care practitioners have a legal obligation to take action and provide treatment, with consent if they can obtain it, but without consent if it cannot be obtained.

In the course of assessing or treating children/young people they sometimes give information that indicates they or someone else are not safe. Is a health care practitioner protected in taking action?

This is a privacy rather than consent matter. Practitioners are protected by the exemption to rule 11 of the Health Information Privacy Code 1994, if they believe on reasonable grounds *that the disclosure is necessary to prevent a serious and imminent threat to the life or health of the individual concerned.*

If the child has been, or is likely to be, ill-treated, abused, neglected, deprived or physically, sexually or emotionally harmed a practitioner is protected from all legal claims and disciplinary proceedings if the concerns are reported in good faith to the Children, Young Persons and their Families Service or the police (Children, Young Persons and Their Families Act 1989 (ss. 15, 16). (For further information see discussion on Children, Young Persons and Their Families Act 1989 in the next section.)

Are there other situations in which a practitioner may disclose personal health care information without authorisation from the person concerned or their representative?

There are a range of exceptions to rule 11 of the Health Information Privacy Code 1994. Some of these are discussed under the Code in the next section of this report.

Section 22C of the Health Act 1956 also refers to disclosure of health information and lists a range of persons to whom, and purposes for which, information may be disclosed. These include the police, social workers in the Children, Young Persons and their Families Service, and any funder for purposes of exercising or performing any of that funder's powers, duties, or functions under the Health and Disability Services Act 1993.

Do health care providers have to disclose health information to other health providers?

Section 22F of the Health Act requires that health information be released to a person at their request, or that of their representative, or at request of another health service providing health care to that person. There are exceptions whereby:

- disclosure would be contrary to the patient's interests
- the agency has reasonable grounds for believing the patient does not want the information disclosed
- refusal is authorised by the Health Information Privacy Code.

What special issues arise when children are from Māori and Pacific families?

Relevant cultural issues are discussed in Part I (section 4) of this publication. Children of all cultures and/or their legal representative are entitled to give consent under the Code of Health and Disability Services Consumers' Rights. However, children and young people of some cultures, and their families, are likely to be more comfortable and make good decisions if they are offered the opportunity to involve other family, and perhaps wider family and community members. The extent to which this is desirable will depend on the circumstances and complexity of the intervention being considered and the wishes of the child/young person and their parents.

Within an agency (for example, a hospital) it is not a breach of the Health Information Privacy Code to pass on information to another staff member, for example Māori staff, for the purposes of involving them in discussions with the family. However, where support is being sought from outside an agency, that is from the wider community, authorisation to pass on information and invite someone other than the parents and child to be involved should be sought. The health agency (practitioner) will need to consider whether it is desirable and practical to obtain authorisation to disclose information.

The exception to this is where the information has clearly been sought for the purpose of sharing it with other agencies. In this situation the purpose for which the information is being collected should be discussed with the child/young person and/or their representative.

What are some of the particular issues that occur in mental health?

Making a decision about whether an individual has the capacity to consent can be difficult and require, in addition to considering intellectual maturity, careful professional judgement about whether the child/young person's mental state interferes with their capacity to consent to assessment or treatment. Where proxy consent is required there will be times when the mental health status of the proxy, and their ability to assess the needs of the child in an unbiased way, are factors to be carefully assessed. In at least some cases where a child/young person has a mental illness, or serious behaviour disorder, family dysfunction can impede rational decision-making and motivation to be involved in treatment. In some cases 'treatment' may involve more than one member of the family, all of whom have a right to give informed 'consent', as in the case of family therapy.

Where it is judged (by the mental health professional involved) that a child/young person's capacity to give consent is reduced, a legal representative (usually a parent) can consent on the child/young person's behalf or an order made for compulsory treatment. Children who are judged not to have the capacity to consent still have a right to information about themselves and their treatment.

For children/young people under 16 it will generally be less distressing for all concerned to seek parental consent rather than to take action under the Mental Health (Compulsory Assessment and Treatment) Act 1992 ss. 85–90.

What are some of the particular consent issues that arise when children/young people have disabilities?

The child/young person with the disability has the right to be treated with the same respect for personal integrity, autonomy and self-determination as any other person. Capacity to consent is a crucial issue and practitioners and caregivers must judge carefully the level of information the client can understand. Care must be taken not to assume lack of capacity to consent.

Parents (or other guardians) may make decisions as representatives when a child/young person's capacity is judged to be severely compromised. However the child retains his or her right to information at a level he or she can understand even when unable to consent.

The views of parents, caregivers, child or young person and practitioner may not always coincide and each situation will need to be treated with sensitivity and respect and time allowed for issues to be discussed. In some situations it may be advisable to seek an independent 'advocate' to represent the views and/or interests of the child.

The issue of sterilisation of a young person with a disability is ethically fraught. Sterilisation is a highly invasive and potentially irreversible procedure and should only be considered as a last resort. Caregiver convenience is not a valid reason for performing sterilisation.

Effective alternatives exist for the management of contraception and menstrual discomfort. In 1990 Mr Justice Hillyer authorised the sterilisation, by hysterectomy, of a 15-year-old girl with an intellectual disability after a surgeon was unwilling to operate because of legal uncertainty despite parental consent. In the judge's view the consent of the Court was not required in a case where the young person is unable to give valid consent and the parents are authorised by s. 25(3) of the Guardianship Act to give consent in these circumstances. He placed considerable responsibility on doctors to ensure that informed consent is given in such cases and is for the benefit of the young person.

However, parents do not have the authority to give substitute consent once their offspring with disabilities reach adulthood. The Protection of Personal and Property Rights Act 1998 requires that it is necessary to go to court to sterilise an adult with a disability; less protection appears to be given to children with disabilities than to adults, despite their vulnerability. This means that there is a great responsibility on doctors to assess the capacity and wishes of the child/young person very thoroughly, to assess the viability of alternatives, to assess the risks and to examine the motivation of the person seeking the sterilisation.

Are there any consent implications for well child care and integrated care?

Home visiting

Essentially, any health care service delivered in a child's home can be described as 'home visiting' and the usual requirements for consent for medical treatment apply. Sometimes the term is used to define intensive home visiting programmes such as that being set up in the Family Start programmes. In this case services provided are broader than health but may involve actions that could directly be described as health care, for example parenting information or advice on immunisation. In addition to the provision of personal support and information, one of the home visitor's primary tasks is to encourage the family to access relevant health and other services.

Informed consent must be sought when including a child and family on a programme. Although such a programme may not strictly be defined as a health service, clearly the family is more likely to make constructive use of the service if they understand its purpose and want to co-operate with the programme.

Authorisation should be sought when information is to be disclosed on referral to another agency. The Health Information Privacy Code does not require that individuals authorise release of information on referral provided that they were made aware that the information would be passed on before it was collected. In other circumstances authorisation must be sought before referral is made.

As discussed previously, practitioners are protected from civil or legal action in disclosing material about a child or young person when the child is in danger of child abuse or the child or any other person is in danger of harm to themselves or others.

Consent will be necessary when health information is being used for purposes of research and evaluation.

Co-ordinated/co-operative care

A range of initiatives (for example, the Strengthening Families local co-ordination initiative, integrated care, family health teams) are aimed at improving health (and sometimes education and welfare) outcomes for children. They aim to improve the availability and coordination of services for the child and family through improving provider communication and co-operation and facilitating family access to services. Essential to such a service is the free flow of information about the child's condition and needs.

When information passed between different agencies involves identifiable personal information, the parents' (and child's if old enough) authorisation to release that information should be sought. Families must be fully informed about what information is collected and what is passed on and be free to agree or refuse to authorise disclosure (subject to exceptions under the Health Information Privacy Code). In addition to publicising the procedures used in these circumstances through posters and pamphlets, providers should take responsibility for discussing the procedures and their implications with families.

When different providers and agencies from different sectors work together on joint projects or in addressing the needs of individual families, it will be important that they discuss and reach agreement about consent and authorisation issues. Their agreement could take the form of formal or informal protocols, which may include the issues of what information is given to families, when and how it is given and how consent to involvement in a programme and authorisation to share material is obtained and recorded.

A related issue is that of shared databases. These have advantages for children in providing health care practitioners with up-to-date information about medical care and well child care, but when information is available to more than one agency parents will need to be fully informed about what information is stored and who has access to it, and have the right to choose not to be part of the system.

Who can consent to a child being involved in health-related research?

The ethics of involving children in research, particularly in non-therapeutic research, are complex and these are discussed elsewhere.¹ Guidelines have been developed in other parts of the world which address the issue of when and how children should be involved in health research. The potential risks of research must not outweigh the potential benefits.

¹ Peart N, Holdaway D. 1998. Legal and ethical issues of health research with children. *Childrenz Issues* 2(2): 42–46 Otago: University of Otago.

The general approach suggested in this document in regard to consent to treatment seems an appropriate one to apply in situations where children are involved in research. That is, where a child is old enough to understand, their consent must be sought, and where it is withheld the child should not be included. With the child's agreement their parents should also be involved but their view should not overrule that of the child.

In circumstances where a child does not have the capacity to consent s. 10 of the New Zealand Bill of Rights 1990 (every person has the right not to be subjected to medical or scientific experimentation without that person's consent) might be interpreted to prevent proxy consent and thus preclude children from being included in health research unless they are competent to give informed consent. This could have considerable implications for therapeutic research and for safe non-therapeutic research which could be of benefit to a wide range of children. Interpretation of the word 'experimentation' is a crucial issue. This matter requires further clarification. Section 10 of the New Zealand Bill of Rights is based on Article 7 of the International Covenant on Civil and Political Rights to which New Zealand is a party. However s. 10 of the Bill of Rights is more restrictive than Article 7.

Practitioners undertaking research involving infants and children should discuss relevant consent issues with an ethics committee and legal advisors.

Still don't feel confident?

In most practice situations, obtaining consent should not be problematic provided the basic principles outlined earlier are adhered to. When practitioners feel uncertain as to how to proceed in any particular situation the following options are available and should be used when appropriate:

- consult agency policy or guidelines
- discuss the matter with experienced colleagues
- discuss the matter with your organisation's legal advisor
- consult a local ethics committee
- contact the Office of the Health and Disability Commissioner
- contact the Office of the Privacy Commissioner.

Part III: Legislation

In this section legislation is reviewed and some further implications for practice are explored. A range of legislation is relevant to consent to health care for children/young people, some specific to children and some related to consent generally. Relevant legislation is listed but readers may also wish to consult the actual statutes. Some of the possible implications of legislation are untested in New Zealand courts and legal advice should be sought on specific situations where there are difficulties that cannot be resolved informally.

Legislation is reviewed in date order, starting with the most recent.

Code of Health and Disability Services Consumers' Rights (1996)²

This Code is a regulation under the Health and Disability Commissioner Act 1994 and applies to all health and disability support services in New Zealand. It gives rights to all health and disability consumers and places obligations on people and organisations providing services. Code rights should not be read in isolation. Children are entitled to all the rights under this Code. If a consumer believes his or her rights have been breached they may make a complaint to the individual providing the service, any persons authorised to receive complaints about that provider, an independent advocate provided under the Health and Disability Commissioner Act 1994, or the Health and Disability Commissioner.

The Code provides that no health or disability service can be provided to a consumer without his or her informed consent (right 7(1)). The elements of consent are effective communication, full information and freely given, and competent consent. These elements are covered by rights 5, 6 and 7 of the Code.

The Code makes a presumption of competence (right 7(2)). It presumes that every consumer is competent to make an informed choice and to give informed consent unless there are reasonable grounds for believing the consumer is not competent. A practitioner must judge whether a particular child is competent to give informed consent to a particular procedure, depending on the child's understanding, and maturity, and the gravity of the procedure. While the views of the parent or carer as to the child's competence may be taken into account, it is the practitioner's responsibility to form an independent judgement on the matter. Even when a child is regarded as not competent to consent to a particular treatment they still retain their other rights in the Code, including the right to be provided with information suitable to their age, maturity and interest, and this should be provided in a manner that enables them to understand it.

Therefore, there is no particular age at which all children are deemed to be competent to consent to all health and disability support services. Under the Code the actual age of the child is not the important question but rather the level of understanding of the child. The fact that the Code applies to all consumers and does not discriminate on grounds of age means that children must be consulted in regard to consent in a manner relevant to their age. If children are not old enough to understand, someone authorised to consent on their behalf may do so. The Code does not define who this is, but other law on this matter applies (that is, parents or legal guardians (Guardianship Act 1968)).

The Code is subject to other legislation and common law. Therefore practitioners need not obtain consent from either the child or the parent/guardian before performing services in lifethreatening emergency situations (right 7(1) of the Code enshrines the common law exception of necessity) and when administering a blood transfusion to a person under 20 as provided for in the Health Act 1956, for example.

² The full text of the Code is given in Appendix 1.

Health (Immunisation) Regulations 1995

These regulations (pursuant to s. 117 of the Health Act 1956) require that all children born from January 1995 have an immunisation certificate to show whether they are fully immunised. There is no compulsion to have children immunised. The certificate may be signed at the 15-month immunisation by a nurse or doctor (or at any other time if parents choose against immunisation). When a child starts at an early childhood centre, kohanga reo or primary school, his or her parents will be asked to show the certificate. The information will be stored in a register, which parents may check.

A Medical Officer of Health can check the register if there is a threat of vaccine-preventable disease in an area. Non-immunised children may be required to stay at home until after the threat is over. The regulations do not limit the right of any child to be enrolled at or attend any early childhood centre or primary school.

Privacy Act 1993 and the Health Information Privacy Code 1994

The Privacy Act 1993 provides a set of principles with which agencies dealing with personal information must comply. These principles cover the collection, storage, use and disclosure of information, and also set out individuals' rights of access to information about themselves. In the health sector these principles have been modified by the Health Information Privacy Code 1994.

A health agency must ensure that before collecting health information from the child/young person, the child/young person is aware of the reasons for collecting that information. These obligations are similar to, but do not mirror, the requirements for 'informed consent'. Compliance with rule 3 will not necessarily mean that informed consent has been granted, and obtaining informed consent will not necessarily comply with rule 3. There are several situations where the rule does not need to be complied with, such as where compliance is not reasonably practicable.

A health agency can refuse to allow a child or young person access to his or her information if, *in the case of an individual under the age of 16, the disclosure of that information would be contrary to that individual's interests* (s. 29(1)(d)) and for a number of other reasons listed in ss. 27–29 of the Act. This situation arises when there has been a request from the child or representative for access to the information.

Under the Health Information Privacy Code, a health agency must not disclose health information unless one of the exceptions under rule 11 apply. Disclosure to a 'representative' is permitted where the individual is dead or unable to exercise his or her rights. Children may or may not be able to exercise their rights, depending on their level of maturity and understanding. If a child is unable to exercise his or her right because he or she is sick or too young, information can be disclosed to a representative. 'Representative' is defined as:

where the individual is under the age of 16, that individual's parent or guardian.

If a clinician does not want to disclose information to a parent (for example, where they suspect the parent of abusing the child), they may be entitled to refuse to give the information where the disclosure would be contrary to the [child's] interests, or if one of the other reasons set out in the Act would apply.

Other reasons for withholding information are when disclosure:

- would be likely to endanger the safety of any individual (s. 27(1)(d)), or
- would involve the unwarranted disclosure of the affairs of another individual or of a deceased individual (s. 29(1)(a)).

Note: These conditions are applicable only where there has been a request by the representative or by the child or young person themselves.

Parents do not have an automatic right to all information about their mature children. The Code does not draw a distinction between children and adults, and essentially adopts an understanding-based test for the ability to exercise rights under it. Just as the views of a mature young person must be listened to and taken into account in respect of treatment, so should their views be ascertained and considered in respect to disclosure of personal information.

In some cases the need to disclose has been anticipated at the point of obtaining the information and disclosure was one of the purposes for which it was obtained. The patient would normally have been advised of the purpose when the information was collected and that in these circumstances their consent to have the information disclosed is therefore not required.

In the situation where the person receiving treatment does not have the capacity to consent, consent needs to be sought from another, who needs to have adequate information to grant informed consent. Thus a child may be told that the information they are giving about themselves will be used for the purposes of gaining their parent's consent to their treatment.

When disclosure of information was not one of the purposes for which information was collected, information can be disclosed without authorisation from the patient or their representative if another law authorises or requires it.

Under rule 11 of the Health Code there are a number of exceptions which might apply to making unauthorised disclosures. They are discretionary, and health professionals cannot be *required* to disclose simply because one of the exceptions applies.

Sarah Kerkin, in her paper 'Disclosing children's health information: a legal and ethical framework' (see Appendix 2), gives practice advice:

The approach which most closely accords the notions of autonomy and dignity central to the Health Information Privacy Code and the notions of trust and respect

central to good clinical practice, is that of anticipated disclosure. Agencies can – and should – establish information handling policies which are based on purpose and openness. While dealing with mature minors, be open with them if parents’ consent to treatment will be sought: tell them that a certain amount of information will have to be disclosed in order to obtain their parents’ consent. Try to be sufficiently flexible to accommodate their concerns. That way, health professionals will comply with the law and ethical codes, while upholding the trust so fundamental to the therapeutic relationship.

Mental Health (Compulsory Assessment and Treatment) Act 1992

(Sections 10, 13, 15, 29, 30, 58, 59, 60, 61, 62 and 63)

This Act sets out procedures for the compulsory assessment and/or treatment of people who are or may be suffering from a mental disorder. Under this Act applications for compulsory assessment can be made when:

- a medical practitioner considers that there are reasonable grounds for believing that the proposed patient may be mentally disordered (the criteria for establishing the existence or otherwise of a mental disorder are given in the Act)
- a medical practitioner considers that there are grounds for believing that the proposed patient is mentally disordered
- the Court considers that the patient is mentally disordered.

Under treatment orders patients can be required to accept either community or inpatient treatment. A patient who is subject to a compulsory treatment order is ‘required to accept such treatment for mental disorder as the responsible clinician shall direct’ during the first month of treatment of the currency of the compulsory treatment order and thereafter if a psychiatrist appointed by a Review Tribunal considers that treatment is in the patient’s best interests. In all other cases (except emergency treatment where the patient is unable to consent) a patient’s written informed consent to treatment must be obtained, and may be withdrawn at any time.

There are a number of sections of the Act which refer specifically to children and young persons (ss. 86, 87, 88, 89 and 90).

The following guidelines come from the Director-General of Health’s guidelines on the Act (1997):

Part VIII of the Act contains specific provisions governing the treatment of patients and proposed patients who are under the age of 17 years and who are subject to the Act. There are several key points to note:

Section 86 states that ‘wherever practicable, an assessment examination of a person who is under the age of 17 years shall be conducted by a psychiatrist practising in the field of child psychiatry’.

For all practical purposes, a young person aged 16–19 years or over, may be treated as if an adult for purposes of giving consent. Note that ‘in respect of a patient who has attained the age of 16 years, the consent of a parent or guardian to any assessment or treatment for mental disorder shall not be sufficient consent for the purposes of this Act’ (s. 87).

A child/young person and at common law, even a child under the age of 16 years may give a valid and effective consent, if he or she has a sufficient understanding of the significance of the proposed treatment. It all depends on the maturity of the individual child/young person; the effect at the relevant time of the particular disorder; and the seriousness of the matter for decision. If a child/young person under the age of 16 years is able to give consent, the consent of a parent/guardian is not necessary. If a child/young person under the age of 16 years is unable to give consent, the consent of a parent/guardian is necessary (except in an emergency or as authorised by sections 57 to 59). It is important to remember the role of families in the care of children and young people who are mentally ill. Responsible clinicians should ensure that families are actively involved in the management of such patients.

Note that the requirement to inform the patient about the treatment (risks and side effects) is not displaced by the fact that a parent or guardian is giving consent to treatment.

New Zealand Bill of Rights 1990

This Act is intended to ‘affirm, protect, and promote human rights and fundamental freedoms in New Zealand; and to affirm New Zealand’s commitment to the International Covenant on Civil and Political Rights’. It applies to all branches of government, and to any person discharging any public function, power or duty by law. It applies to all individuals regardless of age.

The relevant sections with brief descriptions of their contents follow.

Section 8

No one shall be deprived of life except on such grounds as are established by law and are consistent with the principles of fundamental justice.

Section 10

Every person has the right not to be subjected to medical or scientific experimentation without that person’s consent.

Section 11

Everyone has the right to refuse to undergo any medical treatment.

Section 13

Everyone has the right to freedom of thought, conscience, religion, and belief, including the right to adopt and to hold opinions without interference.

Section 15

Every person has the right to manifest that person's religion or belief in worship, observance, practice, or teaching, either individually or in a community with others, and either in public or in private.

Section 20

A person who belongs to an ethnic, religious or linguistic minority in New Zealand shall not be denied the right, in community with other members of that minority, to enjoy the culture, to profess or practise the religion, or to use the language, of that minority.

These rights are subject to s. 5 which provides:

. . . the rights and freedoms contained in this Bill of Rights may be subject only to such reasonable limits prescribed by law as can be demonstrably justified in a free and democratic society.

Parents who tried to claim that the Bill of Rights guaranteed them freedom of religion, including the right to bring up their children and make medical decisions for their children in accordance with those beliefs, were overruled by the Court of Appeal, which stated:

We define the scope of parental right under section 15 of the Bill of Rights Act to manifest their religion in practice so as to exclude doing or omitting anything likely to place at risk the life, health and welfare of their children.³

It is very unlikely that rights to manifest religious or cultural beliefs as provided for under the Bill of Rights Act could be used to deny a child the right to life-saving or other essential treatment.

The Children, Young Persons and Their Families Act 1989

Section 16 of this Act protects persons reporting ill treatment or neglect of a child from civil, criminal or disciplinary proceeding unless the information was supplied in bad faith. For child health practitioners this means that it is not essential to seek authorisation from a child or parent in order to disclose information in situations where child abuse is known or suspected. It is good practice to inform a family and/or a child, if that child is old enough to understand the action, that a notification is being made. The exception to this is when informing the child or family would place the child or health practitioner at risk in any way

³ Re J (An Infant) [1996] 2 NZLR 134, 146.

or lead to interference with evidence that may be needed for investigation or criminal proceedings.

There are other provisions which authorise release of information, including documentation, when this is required for investigation into a care and protection matter (ss. 59 to 66).

This Act has various provisions which, in certain circumstances, dispense with parental rights to give or refuse consent to medical, psychiatric and psychological assessment and treatment. This can arise when a court orders a medical examination or when the Director-General or some other person or agency has been given guardianship of a child/young person (ss. 49–53, 96 and 97, 178–181, 196 and 333). Child health practitioners should ask a relevant employee of the Children, Young Persons and their Families Service for information about the authority on which examinations or treatment are being requested and for an explanation of the relevant law.

Other provisions of this Act are supportive of actions which underlie good practice in consent matters. The general principles (s. 5) of the Act include taking into account the child's wishes and consulting the wider family when decisions are made about a child. Section 6 makes the welfare and interests of the child paramount in matters relating to the administration of the Act.

Contraception, Sterilisation and Abortion Act 1977

The repeal of s. 3 of this Act in 1990 means that there is no restriction on the supply of contraceptive advice, or on medical practitioners prescribing contraception to young people under 16 without consent from their parents.

Access to abortion is not restricted on grounds of age (Guardianship Act 1968). A child or young person must undergo the same process of counselling and approval by a certifying consultant as any other woman. The consent of a parent or guardian is not required in order for the young person to access abortion information or services.

These provisions mean that the confidentiality of children/young people is ensured in regard to highly personal and sensitive advice and treatment. There are some circumstances where a practitioner may advise a child/young person to seek their parents' support – this will depend on the child's family circumstances, the nature of family relationships and the young person's wishes.

Other sections of this Act make special provisions for people who have custody or care of 'females' with intellectual disabilities to consent to contraception and abortion on their behalf. No one can consent to the sterilisation of another person if that other person lacks capacity to consent on their own behalf by reason only of age (ss. 4, 7 and 34).

Guardianship Act 1968

Under this Act (s. 10B) an application can be made to the Family Court or the High Court for guardianship orders to be made in favour of the Court and allow a person to act as

agent for the Court. In circumstances where the parents (and/or the child) refuse to consent to an essential treatment for example, on religious grounds, a child health practitioner can apply to the Court to have it appointed guardian of the child for the purposes of consenting to treatment.

In a very recent case ‘Baby L’, a successful application was made to the High Court to have the Court made guardian when parents were not willing to consent to termination of treatment, in this case life support assistance without which the child was unable to survive. The Court balanced the baby’s right to life with her right to be free from discomfort and pain, and took into account her parents’ ‘deeply felt wish’ for her life to be prolonged as long as possible. The judges said the child’s welfare was the first and paramount consideration. The Court made the child’s specialist its agent and life support was discontinued after the child returned home.

Section 25(1) of this Act means that anyone who has reached the age of 16 is regarded as an adult for the purposes of medical decision-making, and a health practitioner may presume that a young person over 16 has the capacity to consent unless there are reasons, other than age, to doubt capacity.

Under this Act (s. 25(2)) any married person under the age of 16 may consent to donation of blood, or to any medical, surgical or dental procedure (including blood transfusion) to be carried out on him or her. The Act does not otherwise specifically refer to the rights of children/young people under 16 to consent to medical treatment and there has been a presumption that parental consent is necessary with any child or young person under 16. The Act allows consent to be given by a guardian, where there is no guardian; a person acting in the place of a parent; and if no such person can be found, by a District Court Judge or the Director-General of Social Welfare.

The presumption that a parent or guardian must give consent for a medical assessment or treatment to be carried out on a child under 16 is not consistent with common law developments or the Code of Health and Disability Services Consumers’ Rights which take a capacity-based approach. The majority of legal experts consulted during the development of this document advised that consent given by a competent child is sufficient. Given that some uncertainty exists and children’s usual need for their parents’ support and guidance, it would be wise to discuss issues of consent with both parents and children.

Transport Act 1962

The provisions of s. 58C of the Transport Act 1962 allow an enforcement officer to require a person to permit a registered medical practitioner or authorised person to take a blood specimen from a person who has failed an evidential breath test, refused a breath test, a breath testing device is not readily available or the person has been arrested for suspicion of an offence under the Act while under the influence of drugs or alcohol. A person commits an offence and may be arrested without warrant by not complying with the requirements to permit a blood test.

Section 58D allows an authorised practitioner to take a blood sample without a person’s consent on request of an enforcement officer as long as the practitioner believes that the

person is in the hospital or doctor's surgery as a result of an accident, and the practitioner is satisfied that the taking of a blood sample would not be prejudicial to the person's proper care and treatment.

Section 58D(3) provides practitioners with protection from civil or criminal action in respect of the taking of blood under that section without consent.

Crimes Act 1961

The provisions of s. 151 of the Crimes Act 1961 mean that a clinician may be under a legal duty to supply a sick child or young person in his charge with the necessities of life, and is criminally responsible for omitting without lawful excuse to perform such a duty. A health professional who does nothing in the face of a parent's refusal to consent to their child's treatment, if he or she is in danger without that treatment, may be criminally liable if the child dies or suffers as a result. The health professional is obliged to seek a court order to treat the child if all reasonable efforts to obtain the parent's understanding and support have failed.

Section 152 places a similar responsibility on parents in regard to providing the necessities of life.

Health Act 1956

This Act is currently under review and a bill will be drafted after public consultation is completed. Practitioners will need to inform themselves about the consent implications of the new act when it is passed.

The Act curtails the individual's rights to consent in various circumstances, most of which are related to the powers of medical officers to require notification, examination and intervention in the cases of certain infectious diseases (ss. 59, 70, 74 and 88).

Section 22C authorises disclosure of health information to a range of authorities including the Police, the Children, Young Persons and their Families Service and the funder.

Section 22F requires release of health information at the patient's or their representative's request or that of another provider unless:

- disclosure would be contrary to the patient's interests
- the agency has reasonable grounds for believing the patient does not want the information disclosed
- refusal is authorised by the Health Information Privacy Code.

Under s. 125 persons authorised by the Minister (power is delegated to the Director-General of Health) may examine (but not treat) children in schools without parental consent. The authorised person may notify the child's parents or guardians, or any other person believed to be concerned with the child's welfare, of the results of the examination. However, there is no explicit requirement that this should be done.

The circumstances in which child examinations may occur are defined in guidelines which specify that services should be provided with the permission of the management and/or the board of trustees of the school or early childhood centre and should only happen at the school or early childhood centre. Use of s. 125 should be restricted to situations where the consent of a parent or guardian has not been obtained and the requirement for parental consent would prevent the carrying out of routine examination, or there would be risks to the child and/or other children if the examination were not carried out, for example, in situations of suspected abuse and neglect.

Section 126B of the Health Act protects medical practitioners from civil or criminal proceedings for administering blood transfusions without consent to any person under the age of 20 years as long as the judge is satisfied that the transfusion was (in the opinion of the person administering the transfusion) necessary to save life, or to prevent permanent injury or prolonged and avoidable pain and suffering. The judge must also be satisfied that there was no time to obtain consent from those legally entitled to give it. It is therefore advisable, if there is time, to seek consent to give a transfusion, and if consent is withheld, to seek an order for guardianship of the court.

Tuberculosis Act 1948

This Act dispenses with some consent requirements in that it authorises notification to the Medical Officer of Health and can make examination and treatment compulsory.

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Appendix 1: Code of Health and Disability Services Consumers' Rights

1. Consumers have rights and providers have duties–
 - (1) Every consumer has the rights in this Code.
 - (2) Every provider is subject to the duties in this Code.
 - (3) Every provider must take action to–
 - (a) Inform consumers of their rights; and
 - (b) Enable consumers to exercise their rights.
2. Rights of consumers and duties of providers–

The rights of consumers and the duties of providers under this Code are as follows:

Right 1: Right to be treated with respect

- (1) Every consumer has the right to be treated with respect.
- (2) Every consumer has the right to have his or her privacy respected.
- (3) Every consumer has the right to be provided with services that take into account the needs, values, and beliefs of different cultural, religious, social, and ethnic groups, including the needs, values, and beliefs of Māori.

Right 2: Right to freedom from discrimination, coercion, harassment, and exploitation

Every consumer has the right to be free from discrimination, coercion, harassment, and sexual, financial, or other exploitation.

Right 3: Right to dignity and independence

Every consumer has the right to have services provided in a manner that respects the dignity and independence of the individual.

Right 4: Right to services of an appropriate standard

- (1) Every consumer has the right to have services provided with reasonable care and skill.
- (2) Every consumer has the right to have services provided that comply with legal, professional, ethical, and other relevant standards.
- (3) Every consumer has the right to have services provided in a manner consistent with his or her needs.
- (4) Every consumer has the right to have services provided in a manner that minimises the potential harm to, and optimises the quality of life of, that consumer.
- (5) Every consumer has the right to co-operation among providers to ensure quality and continuity of services.

Right 5: Right to effective communication

- (1) Every consumer has the right to effective communication in a form, language, and manner that enables the consumer to understand the information provided. Where necessary and reasonably practicable, this includes the right to a competent interpreter.

- (2) Every consumer has the right to an environment that enables both consumer and provider to communicate openly, honestly, and effectively.

Right 6: Right to be fully informed

- (1) Every consumer has the right to the information that a reasonable consumer, in that consumer's circumstances, would expect to receive, including—
 - (a) An explanation of his or her condition; and
 - (b) An explanation of the options available, including an assessment of the expected risks, side effects, benefits, and costs of each option; and
 - (c) Advice of the estimated time within which the services will be provided; and
 - (d) Notification of any proposed participation in teaching or research, including whether the research requires and has received ethical approval; and
 - (e) Any other information required by legal, professional, ethical, and other relevant standards; and
 - (f) The results of tests; and
 - (g) The results of procedures.
- (2) Before making a choice or giving consent, every consumer has the right to the information that a reasonable consumer, in that consumer's circumstances, needs to make an informed choice or give informed consent.
- (3) Every consumer has the right to honest and accurate answers to questions relating to services, including questions about—
 - (a) The identity and qualifications of the provider; and
 - (b) The recommendation of the provider; and
 - (c) How to obtain an opinion from another provider; and
 - (d) The results of research.
- (4) Every consumer has the right to receive, on request, a written summary of information provided.

Right 7: Right to make an informed choice and give informed consent

- (1) Services may be provided to a consumer only if that consumer makes an informed choice and gives informed consent, except where any enactment, or the common law, or any other provision of this Code provides otherwise.
- (2) Every consumer must be presumed competent to make an informed choice and give informed consent, unless there are reasonable grounds for believing that the consumer is not competent.
- (3) Where a consumer has diminished competence, that consumer retains the right to make informed choices and give informed consent, to the extent appropriate to his or her level of competence.
- (4) Where a consumer is not competent to make an informed choice and give informed consent, and no person entitled to consent on behalf of the consumer is available, the provider may provide services where—
 - (a) It is in the best interests of the consumer; and
 - (b) Reasonable steps have been taken to ascertain the views of the consumer; and
 - (c) Either,—
 - i. If the consumer's views have been ascertained, and having regard to those views, the provider believes, on reasonable grounds, that

- the provision of the services is consistent with the informed choice the consumer would make if he or she were competent; or
- ii. If the consumer's views have not been ascertained, the provider takes into account the views of other suitable persons who are interested in the welfare of the consumer and available to advise the provider.
- (5) Every consumer may use an advance directive in accordance with the common law.
 - (6) Where informed consent to a health care procedure is required, it must be in writing if–
 - (a) The consumer is to participate in any research; or
 - (b) The procedure is experimental; or
 - (c) The consumer will be under general anaesthetic; or
 - (d) There is a significant risk of adverse effects on the consumer.
 - (7) Every consumer has the right to refuse services and to withdraw consent to services.
 - (8) Every consumer has the right to express a preference as to who will provide services and have that preference met where practicable.
 - (9) Every consumer has the right to make a decision about the return or disposal of any body parts or bodily substances removed or obtained in the course of a health care procedure.
 - (10) Any body parts or bodily substances removed or obtained in the course of a health care procedure may be stored, preserved, or utilised only with the informed consent of the consumer.

Right 8: Right to support

Every consumer has the right to have one or more support persons of his other choice present, except where safety may be compromised or another consumer's rights may be unreasonably infringed.

Right 9: Rights in respect of teaching or research

The rights in this Code extend to those occasions when a consumer is participating in, or it is proposed that a consumer participate in, teaching or research.

Right 10: Right to complain

- (1) Every consumer has the right to complain about a provider in any form appropriate to the consumer.
- (2) Every consumer may make a complaint to–
 - (a) The individual or individuals who provided the services complained of; and
 - (b) Any person authorised to receive complaints about that provider; and
 - (c) Any other appropriate person, including–
 - i. An independent advocate provided under the Health and Disability Commissioner Act 1994; and
 - ii. The Health and Disability Commissioner.
- (3) Every provider must facilitate the fair, simple, speedy, and efficient resolution of complaints.
- (4) Every provider must inform a consumer about progress on the consumers complaint at intervals of not more than one month.

- (5) Every provider must comply with all the other relevant rights in this Code when dealing with complaints.
 - (6) Every provider, unless an employee of a provider, must have a complaints procedure that ensures that–
 - (a) The complaint is acknowledged in writing within five working days of receipt, unless it has been resolved to the satisfaction of the consumer within that period; and
 - (b) The consumer is informed of any relevant internal and external complaints procedures, including the availability of–
 - i. Independent advocates provided under the Health and Disability Commissioner Act 1994; and
 - ii. The Health and Disability Commissioner; and
 - (c) The consumer’s complaint and the actions of the provider regarding that complaint are documented; and
 - (d) The consumer receives all information held by the provider that is or may be relevant to the complaint.
 - (7) Within 10 working days of giving written acknowledgement of a complaint, the provider must,–
 - (a) Decide whether the provider–
 - i. Accepts that the complaint is justified; or
 - ii. Does not accept that the complaint is justified; or
 - (b) If it decides that more time is needed to investigate the complaint,–
 - i. Determine how much additional time is needed; and
 - ii. If that additional time is more than 20 working days, inform the consumer of that determination and of the reasons for it.
 - (8) As soon as practicable after a provider decides whether or not it accepts that a complaint is justified, the provider must inform the consumer of–
 - (a) The reasons for the decision; and
 - (b) Any actions the provider proposes to take; and
 - (c) Any appeal procedure the provider has in place.
3. Provider compliance–
- (1) A provider is not in breach of this Code if the provider has taken reasonable actions in the circumstances to give effect to the rights, and comply with the duties, in this Code.
 - (2) The onus is on the provider to prove that it took reasonable actions.
 - (3) For the purposes of this clause, ‘the circumstances’ means all the relevant circumstances, including the consumer’s clinical circumstances and the provider’s resource constraints.

4. Definitions–

In this Code, unless the context otherwise requires,–

‘Advance directive’ means a written or oral directive–

- (a) By which a consumer makes a choice about a possible future health care procedure; and
- (b) That is intended to be effective only when he or she is not competent:
 - ‘Choice’ means a decision–
 - (a) To receive services:

(b) To refuse services:

(c) To withdraw consent to services:

‘Consumer’ means a health consumer or a disability services consumer; and, for the purposes of rights 5, 6, 7(1), 7(7) to 7(10), and 10, includes a person entitled to give consent on behalf of that consumer:

‘Discrimination’ means discrimination that is unlawful by virtue of Part II of the Human Rights Act 1993:

‘Duties’ includes duties and obligations corresponding to the rights in this Code:

‘Exploitation’ includes any abuse of a position of trust, breach of a fiduciary duty, or exercise of undue influence:

‘Optimise the quality of life’ means to take a holistic view of the needs of the consumer in order to achieve the best possible outcome in the circumstances:

‘Privacy’ means all matters of privacy in respect of a consumer, other than matters of privacy that may be the subject of a complaint under Part VII or Part VIII of the Privacy Act 1993 or matters to which Part X of that Act relates:

‘Provider’ means a health care provider or a disability services provider:

‘Research’ means health research or disability research:

‘Rights’ includes rights corresponding to the duties in this Code:

‘Services’ means health services, or disability services, or both; and includes health care procedures:

‘Teaching’ includes training of providers.

5. Other enactments–

Nothing in this Code requires a provider to act in breach of any duty or obligation imposed by any enactment or prevents a provider doing an act authorised by any enactment.

6. Other rights not affected–

An existing right is not overridden or restricted simply because the right is not included in this Code or is included only in part.

Appendix 2: Papers from the Consent and Child Health workshop

Wellington 6 August 1998

Legal and ethical dilemmas

Ron Paterson
Chief Advisor, Services, Ministry of Health

Informed consent is a process. Its elements are that it is:

- voluntary
- informed
- competent.

1) Voluntariness

Consent to health care procedure must be freely given by the consumer or person entitled to consent on that consumer's behalf. This is confirmed by a partial definition in section 2 of the Health and Disability Commissioner Act 1994:

'Informed consent', in relation to a health consumer on or in respect of whom there is carried out any health care procedure, means consent to that procedure when that consent—

(a) Is freely given, by the health consumer or, where applicable, by any person who is entitled to consent on that health consumer's behalf: and

(b) Is obtained in accordance with such requirements as are prescribed by the Code:

In *Re T* [1992] 4 All ER 649, a 20-year-old pregnant woman, admitted to hospital following a car accident, signed a written form refusing consent to blood transfusion after she had been visited by her Jehovah's Witness mother. The English Court of Appeal stated that:

In assessing whether a patient has truly made her own decision doctors should consider:

- (1) the strength of will of the patient. One who is very tired, in pain or depressed will be much less able to resist having her will overborne . . . than one who is rested, free from pain and cheerful.*
- (2) the relationship of the 'persuader' to the patient. Parental and spousal influence requires careful scrutiny, especially on religious belief matters.*

Even for a mature young person, clinicians should be alert to the possibility of coercion or undue influence for example, by parents on religious belief matters.

2) Informed consent

Every consumer [including a child] has the right to the information that a reasonable consumer, in that consumer's circumstances, needs to make an informed choice or give informed consent. (Right 6(2) Code of Health and Disability Services Consumers' Rights).

- Information giving is separate from consent: even if a child is not mature enough to give a valid consent, s/he has a right to receive appropriate information.
- An explanation should be given at the level of the child's understanding and a full explanation must also be made to the child's representative. In regard to the purpose of collection of information, the commentary to Rule 3 of the Health Information Privacy Code 1994 gives guidance.

Requirement to inform representative

Where a child could not be expected to understand fully the explanations required in rule 3, an explanation should be given at the level of the child's understanding, while a full explanation must also be made to the child's representative (if the collection is from the representative). Similar requirements apply to people with mental or intellectual disability.

3) Competency

There are two approaches to deciding competency:

1. The 'status' rule
Children 16 years of age or older may consent to treatment (s 25(1) Guardianship Act 1968).
2. The 'maturity approach'
A child of sufficient maturity, even under the age of 16 years, may consent to treatment. This is based on the House of Lords decision in the *Gillick* case [1985] 3 All ER 402. The decision was noted with approval by the New Zealand Court of Appeal in *Re J* [1996] 2 NZLR 134.

Right 7(2) of the Code of Health and Disability Services Consumers' Rights also supports this approach:

Every consumer must be presumed competent to make an informed choice and give informed consent, unless there is reasonable grounds for believing that the consumer is not competent.

Statutory provisions regarding cultural and religious issues in treating children

A number of statutory provisions are relevant to cultural and religious issues which may arise in relation to health care for children.

Right 1(3) of the Code of Health and Disability Services Consumers' Rights

This right provides that:

Every consumer has the right to be provided with services that take into account the needs, values, and beliefs of different cultural, religious, social, and ethnic groups, including the needs, values and beliefs of Māori.

New Zealand Bill of Rights Act 1990

This Act is intended to affirm, protect, and promote human rights and fundamental freedoms in New Zealand; and to affirm New Zealand's commitment to the International Covenant on Civil and Political Rights.

It applies to all branches of government, and to any person discharging any public function power or duty by law.

Sections 10 and 11:

- *Every person has the right not to be subjected to medical or scientific experimentation without that person's consent.*
- *Everyone has the right to refuse to undergo any medical treatment.*

Section 13:

Everyone has the right to freedom of thought, conscience, religion, and belief, including the right to adopt and hold opinions without interference.

Section 15:

Every person has the right to manifest that person's religion or belief in worship, observance, practice, or teaching, either individually or in a community with others, and either in public or in private.

These rights are subject to section 5 which provides:

. . . the rights and freedoms contained in this Bill of Rights may be subject only to such reasonable limits prescribed by law as can be demonstrably justified in a free and democratic society.

Section 126B of the Health Act 1956

This section protects medical practitioners from civil or criminal proceedings for administering blood transfusions without consent to any person under the age of 20 years as long as the judge is satisfied that the transfusion was (in the opinion of the person administering the transfusion) necessary to save life, or to prevent permanent injury or prolonged and avoidable pain and suffering. The judge must also be satisfied that there was no time to obtain consent and that attempts were made to obtain consent from those legally entitled to give it, unless it was impractical to do so in the time available. There are clear limits to the power of this section – see Re J [1996] 2 NZLR 134, discussed below.

Crimes Act 1961

Section 151 Duty to provide the necessaries of life

- (1) *Every one who has charge of any other person unable, by reason of detention, age, sickness, insanity, or any other cause, to withdraw himself from such a charge, and unable to provide himself with the necessaries of life, is ... under a legal duty to supply that person with the necessaries of life, and is criminally responsible for omitting without lawful excuse to perform such a duty if the death of that person is caused, or if his life is endangered or his health permanently injured, by such omission.*

In the present context this means that a clinician is under a legal duty to supply a sick child or young person in his charge with the necessaries of life, and is criminally responsible for omitting without lawful excuse to perform such a duty. A health professional who does nothing in the face of a parent's refusal to consent to his or her child's treatment, if s/he is in danger without that treatment, may therefore be criminally liable if the child dies or suffers as a result.

Section 152 of the Crimes Act 1961 [*Duty of parents or guardian to provide necessaries*] places similar responsibilities on a parent and guardian.

Case law regarding cultural and religious issues in treating children

Some of the above statutory provisions were addressed by the courts in the following cases.

Cultural rejection of Western medicine

The limits of parental autonomy in consenting to medical treatment of a child come sharply into focus in cases where, for ethnic or religious reasons, parents refuse to authorise treatment despite advice that it is in the child's best medical interests. Re Norma [1992] NZFLR 445 illustrates the role that the courts may play in the resolution of an impasse between parents and medical advisers.

In this case there was a profound clash of New Zealand and Samoan cultures. A young child suffering from Ewings sarcoma was recommended limb amputation and chemotherapy. The parents refused amputation but allowed six weeks of chemotherapy before they removed her from hospital. She was subsequently treated at home according to traditional Samoan medicine. After several months of discussion the hospital doctors concluded that Norma needed to undergo further investigative procedures. The parents refused to let the child return to hospital and faced with the impasse the Department of Social Welfare applied to have N made a ward of the court, and for orders that the Director General of Social Welfare be authorised to consent to any medical or surgical procedures, as advised by the hospital doctors.

Tompkins J said:

There can be little doubt that where what is sought is consent to essential medical treatment that cannot otherwise be obtained, the Court has jurisdiction to place the child under the guardianship of the Court for the purpose of giving this consent.

The test applied is the ‘best interests of the child’ which does not refer solely to the child’s best medical interests. Tompkins J recognised that:

a child’s welfare is bound up with his or her family [and that] if a course of action is likely to cause serious distress and disruption within a family, that too is a factor which must bear on the welfare of the child and therefore weigh with the Court.

Tompkins J felt compelled to accept the advice of the hospital doctors that Norma was still suffering from bone cancer and that the 50 percent chance of preventing the spread of her cancer dictated that N receive the benefit of modern treatment authorised by the Court, as guardian.

In *Director General of Social Welfare v J* (HC (Auck) M 708/97 November 1997, Salmon J) a two-year-old boy was placed under the guardianship of the High Court (pursuant to s. 9 Guardianship Act 1968) to enable treatment for suspected testicular cancer. The parents held the firm belief that their son did not have cancer, the removal of his testicle would prevent him having children, and that they would cure him with Cambodian herbal treatments. The medical evidence showed a 99 percent chance that the child had a malignant tumour to be confirmed by biopsy and that the child’s only chance of survival was removal of the testicle followed by chemotherapy. There was not evidence to support the contention that the parents’ herbal remedies would cure the cancer. The case involved a clear-cut life/death situation leaving the Court no option but to make the guardianship orders. The child’s best interests clearly overrode the parents’ objections.

Christian beliefs that God will heal

In *Liu* [1996] HC (Auck) M81/96 Tompkins J made a 12-year-old boy a ward of the court, and appointed a medical specialist as agent to authorise surgery to re-attach the partially detached retina of the boy’s right eye. The boy had already lost the sight of his left eye, after painful, unsuccessful surgery. The judge balanced the religious beliefs of both the boy and his parents, who believed God would heal his sight, against the medical prognosis of total blindness without the surgery, but a 70 percent chance of success if the operation

was performed. The paramountcy of the boy's welfare (Guardianship Act 1968 s. 23) persuaded the judge that treatment should proceed.

Jehovah's witnesses and blood transfusions

In *Re J* [1996] 2 NZLR 134 Ellis J had made a three-year-old boy, whom doctors considered in need of a blood transfusion after a severe nose bleed, a ward of the Court and appointed a medical specialist to act as agent to consent to any medical treatment involving blood transfusion, over the objection of the boy's Jehovah's Witness parents. The Court of Appeal dismissed the parents' appeal, noting that *the parents right to practise their religion cannot extend to imperil the life or health of the child.*

The Court confirmed that s. 126B of the Health Act 1956 does not provide an exclusive statutory mechanism, and that an application to place the child under the guardianship of the Court and seek prior consent to a blood transfusion, may be brought *where time and circumstances permit.* Before the Court, as guardian, authorises a transfusion to a child in the face of parental opposition:

there must be real or substantial risk that the patient's condition will in the course of medical care be such as, on accepted medical practice, would call for blood transfusion and that in the event that condition develops a blood transfusion will be necessary.

Parents who refuse to consent to life-saving treatment of young children for 'quality of life' reasons

Re B [1981] 1 WLR 1421 concerned an infant born with Down's syndrome and an intestinal blockage which would have been fatal unless operated on. Her parents took the view that not to operate was the kindest thing to do in the circumstances and refused to consent to surgery. A local authority applied to have the child a ward of the Court and asked the Judge to authorise consent to the operation.

In the English Court of Appeal, Templeman LJ said:

It is a decision which of course must be made in the light of the evidence and views expressed by the parents, and the doctors, but at the end of the day it devolves on this court to decide whether the life of this child is demonstrably going to be so awful that in effect the child must be condemned to die, or whether the life of the child is so imponderable that it would be wrong for her to be condemned to die.

Dunn LJ agreed saying:

I have great sympathy with the parents in the agonising decision to which they came. As they put it themselves, "God or nature has given the child a way out" but the child now being a ward of court . . . the fact of the matter is that the court now has to

make the decision . . . the child should be put into the same position as any other mongol child and must be given the chance to live an existence.

In *Re T* [1997] 1 WRL 242 parents of a child who was born with a liver defect did not wish their child to undergo transplant surgery and refused to consent to an operation, despite the advice of doctors. The parents were both health care professionals. The child and his parents had gone to live overseas. The English Court of Appeal set aside the original judge's decision (that the child must be returned to the United Kingdom to undergo surgery) saying:

that the judge had erred in not weighing the balance of reasons against the treatment which might be held by a reasonable parent on much broader grounds than that of clinical assessment of the likely treatment, and his decision could not stand . . .

The key point was that the best interests of the child went beyond clinical interests. The Court needed to consider both clinical issues (the role of the parents in caring for the child post surgery would be critical) and the broader issues relating to the child's wellbeing and quality of life within his own family.

Sterilisation of a child with an intellectual disability

In *Re X* [1990] 2 NZLR 365 Hillyer J authorised the sterilisation, by hysterectomy, of a 15-year-old girl with an intellectual disability. The family and medical experts were of the opinion that the child, who had a severe intellectual disability, would not be able to cope with menstruation. Despite parental consent to the operation the surgeon was not willing to operate because of perceived legal uncertainty. The parents applied for a court order authorising sterilisation.

Hillyer J concluded that the High Court is entitled, in the exercise of its protective jurisdiction, to consent to sterilisation in a young person's best interests. He authorised sterilisation of X by hysterectomy to prevent menstruation, noting that this was not sterilisation for contraceptive purposes.

The judge also pointed out that in fact the consent of the Court was not required, basing his conclusion on s. 25(3) of the Guardianship Act 1968. He concluded that when the consent of any other person to a medical procedure to be carried out is necessary (as it clearly is where the child is unable, because of intellectual disability, to give valid consent), consent may be given by a guardian. The statutory provision does not say that, in such a case, parental consent is sufficient; however, the judge was prepared to read this into the statute.

In the absence of a requirement of Court approval, the medical profession was seen as assuming an important monitoring role:

Doctors will appreciate that they have an obligation to ensure that the operation they are carrying out is a proper one, and that the consent given is a proper consent . . . The medical profession must satisfy itself that the informed consent of the parents is given, and that the consent is for the benefit of the child . . . Individual doctors faced with the responsibility of carrying out such an operation . . . should take full

advice and consultation from those who in their view would be able to advise helpfully on such a matter.

Teenagers who refuse consent to treatment

In England, where there is similar statutory provision to section 25 of the Guardianship Act, the Court of Appeal has suggested that it would be possible to have both a refusal to consent by a competent teenager and at the same time a valid consent by a legal guardian.

There has been much criticism of this view. It would be possible to avoid such an unfortunate result in New Zealand by:

- being cautious in assessment of competency and
- where the teenager is found to be competent, relying on s. 11 of the Bill of Rights, to come to the conclusion that parents/guardians lose the right to give or withhold consent to treatment of that teenager.

The English cases are discussed below.

15-year-old refusing anti-psychotic drugs

In *Re R* [1991] 4 All ER 177 the English Court of Appeal ruled that a 15-year-old girl, undergoing treatment for psychotic tendencies, did not have sufficient understanding to refuse consent to the administration of medication prescribed by her doctors. As the Court put it, R was not ‘Gillick-competent’.

However *Re R* has generated legal controversy because of comments by Lord Donaldson on the extent of parents’ powers in relation to mature children. He stated that:

in the case in which the ‘Gillick-competent child’ refuses treatment, but the parents consent, that consent enables treatment to be undertaken lawfully, but in no ways determines that the child shall be so treated.

In the judge’s terminology, either the mature child, or the parents, may hold the key which unlocks the door of lawful treatment. But since it is left to the doctor to determine which consent to rely upon, the doctor effectively has the power to turn the key.

16-year-old girl refuses treatment of anorexia

In *Re W* [1992] 4 All ER 627 the English Court of Appeal went one step further than *Re T* and authorised medical treatment of an anorexic 16-year-old girl who wanted to continue starving herself. The trial judge had, somewhat surprisingly, found that W, who had endured an appalling childhood, and was in poor physical condition, had sufficient understanding to make decisions about her anorexia nervosa. (The Court of Appeal doubted whether she was in fact competent.)

Lord Donaldson affirmed the rights of parents and doctors to determine a teenager’s medical treatment. The judge stated that:

good parenting involves giving minors as much rope as they can handle without an unacceptable risk that they will hang themselves.

He concluded that:

where the wishes of a minor are themselves something which the doctors reasonably consider needs to be treated in the minor's best interests, those wishes themselves clearly have a much reduced significance.

This decision may lead to a diminution of an adolescent's right to control her own body. The obvious inference from *Re W* is that a mature teenager, or even one who has attained the statutory threshold of 16, may have his or her refusal of consent to medical treatment overridden if the doctor agrees with the parent's view that treatment would be beneficial. This view could be seen as undermining the emerging citizenship of adolescents.

To reiterate, the better view in New Zealand is that, applying the *Gillick* decision and s. 11 of the New Zealand Bill of Rights Act 1990, if a young person is mature enough to give valid consent, or refuse consent, to a health care procedure, that consent or refusal to consent is fully effective (provided that the young person was competent and not coerced at the relevant time) and cannot be overridden by the wishes of parents or guardians.

The Informed Consent Process and the Application of the Code to Children

Annie Fraser
Legal Manager
Office of the Health and Disability Commissioner

1 Introduction

No health or disability service can be provided to a consumer without his or her informed consent (Code of Health and Disability Services Consumers' Rights, right 7(1)). The right to make an informed choice and give informed consent is one of the central elements in the Code of Health and Disability Services Consumers' Rights, a new part of the legislative framework regulating the provision of service. The concept of respect for the intrinsic value and uniqueness of each individual, including children, underlies all the rights within the Code.

The law relating to the ability of children to consent to medical treatment is complex. One thing which is clear is that there is no one particular age at which all children can consent to all health and disability services. Indeed, the development of the law in this area demonstrates a trend away from age-related thresholds, and instead focuses on the competence of the individual child. The Code of Rights reflects this trend. Under the Code,

the relevant question is not what is the age at which a child may validly consent to services, but rather whether the level of understanding of a particular child enables him or her to consent to a particular service. There is no blanket answer to this.

This morning I would like to outline the provisions of the Code of Rights relating to informed consent, discuss their application to children and give some examples of cases considered by the Commissioner. While I cannot promise to convert what is an intrinsically complex matter into a simple checklist for providers, I do hope that discussion of the Code will give a clearer understanding of the principles underpinning the issue.

2 Elements of Informed Consent

In terms of the Code, informed consent is a process rather than a one-off event. The essential elements of this process are effective communication, full information, and freely given, competent consent. These three elements are represented by rights 5, 6 and 7 respectively. While the bulk of this paper deals with right 7 and the ability to consent, it is clear that valid consent cannot be given by someone who doesn't understand what is being consented to. I will therefore address all these rights, which under the Code operate as a group. The obligation under the Code is to take all reasonable action in the circumstances to give effect to these rights.

Effective communication

Many problems of consent arise from poor communication. Right 5 of the Code therefore entitles every consumer to effective communication in a form, language and manner that enables the consumer to understand the information provided to them. Where necessary and reasonably practicable, this includes the right to a competent interpreter. Further, every consumer has the right to an environment that enables both consumer and provider to communicate openly, honestly and effectively.

Depending on the circumstances, creating this environment for children might include one-on-one or group discussions in which appropriate time is allowed for questions to be asked, and honest and accurate answers given. It may also involve using culturally appropriate methods of communication; plain language rather than medical jargon; written or visual explanations; and diagrams, toys or videos. The involvement of family, whānau or other support persons may often be of assistance to aid understanding.

Providing all relevant information

The second essential element of informed consent is to give all relevant information to the consumer. Right 6(2) of the Code gives every consumer a right to information that a reasonable consumer in that consumer's circumstances needs to make an informed choice or give informed consent. In addition, right 6(1) gives consumers a right to the information they would expect to receive, irrespective of whether a particular choice is being made or consent given, and sets out a list of such information. The list is not an exhaustive one, but rather is indicative of the type of information which a provider should make available. In addition, consumers are entitled to honest and accurate answers to questions about services, and are entitled to receive, on request, a written summary of the information

provided. In deciding what information should be given and in what manner and form, the provider must focus on the ability of the consumer to understand the information provided.

3 Consent and the presumption of competence

Right 7(1)

The fundamental right to informed consent is embodied in right 7(1) of the Code, which states that:

services may be provided to a consumer only if that consumer makes an informed choice and gives informed consent, except where any enactment, or the common law, or any other provision of the Code provides otherwise.

The more general language of ‘choice’ is used to reflect the Code’s focus on the active involvement of the consumer in the decision-making process.

Children as consumers under the Code

In recognition that the ability to understand information and make informed choices about particular services is not always tied to the age of the consumer, the Code avoids imposing an artificial barrier on the age at which a child can validly give informed consent to services. Therefore, all the rights in the Code are applicable to consumers of health and disability services, regardless of the age of the consumer, including the right to give informed consent. This does not mean that the age of the consumer should be ignored. Obviously, age is a relevant factor to take into account when determining a child’s competence to make a particular decision. The Code simply recognises that the age of the consumer is only one of a number of factors that should be considered.

The presumption of competence contained in right 7(2) of the Code forms the basis of the Code’s approach to the giving of informed consent by children. The presumption is similar to that which applies in the Protection of Personal and Property Rights Act 1988, and provides that every consumer must be presumed competent to make an informed choice and give informed consent unless there are reasonable grounds for believing that the consumer is not competent. Ultimately, an assessment of whether a particular child is competent to give consent to a proposed procedure will depend on the understanding and maturity of the child, and the gravity of that procedure.

The Code goes on to provide that where a consumer has diminished competence, he or she retains the right to make an informed choice and give informed consent to the extent appropriate to his or her level of competence. The level of ability necessary to consent to treatment with a high degree of risk or complexity or with serious consequences for the child will usually be different from that required to consent to minor and low risk procedures. Thus while a child of 12 may be competent to consent to the setting of a broken limb, he or she may lack the necessary maturity and understanding to consent to heart surgery. The key under the Code is to consider each case on its own facts and not to lay down blanket rules.

The common law

The approach taken by the Code to informed consent by children reflects that adopted by the courts in recent years. In a number of cases the courts have shown a willingness to give a child the right to consent to treatment or services which are relatively minor and for which the child is capable of understanding the nature and consequences. The leading case in this area is *Gillick v West Norfolk and Wisbech Area Health Authority* [1985] 3 All ER 402, a case involving a child under 16 who sought to give consent on matters involving contraception. The English House of Lords held that minors may authorise medical treatment if they are mature enough to understand what is proposed and are capable of expressing their own wishes.

This decision has had wide implications beyond the law relating to contraceptive advice – it also established what is known as the ‘*Gillick* competency’ test for determining when a minor is competent to consent to any medical treatment.

The right to refuse treatment

This test of competence is also relevant when a child seeks to exercise his or her right to refuse treatment and withdraw consent to services under right 7(7) of the Code. However, the scope of this right as it relates to children is uncertain. The English Court of Appeal in a number of cases has sought to deny children the right to refuse consent to treatment, particularly where such refusal may result in death or severe disability, and subsequently ordered the children concerned to be treated without their consent (re *R (A Minor)* and *Re W (A Minor)*).

I am unaware of any cases to date in New Zealand which have directly applied the decisions in these cases. It seems generally accepted that *Gillick* should be followed for a number of reasons, including the importance of ‘mature’ minors being able to seek or refuse health services without fear of parental involvement. I understand that the issue of refusal of services will be addressed in more detail by a later speaker.

Providing consent on behalf of a child

The definition of ‘consumer’ under the Code for purposes of the informed consent provisions includes someone entitled to consent on behalf of the consumer. If a child is not capable of consenting, someone else will be required to do so on his or her behalf. The issue of who is legally entitled to consent on a child’s behalf is not dealt with directly by the Code, and other law on this matter applies. For example, the Guardianship Act 1968 section 25(3) authorises parents and legal guardians to consent to any medical, dental and surgical procedures on a child’s behalf. If a parent or guardian cannot be found, this authorisation extends to persons acting in the place of a parent.

While the Code gives rights to such persons as ‘consumers’ for the purposes of giving informed consent, it is important to remember that the child retains all the other rights and protections in the Code. For instance, where a child is unable to appreciate the consequences of a serious or complicated procedure, they must still be provided with information proportionate to their level of ability to understand. Regardless of whether the child is competent to consent, providers are still obliged to supply the child with

information about the procedure or service which is suitable to their age, maturity and interest, and again, this information must be communicated in a form, language and manner that enables them to understand. Therefore it may be that two alternative sets of information are provided – that which is given to the parent or guardian to enable them to consent, and that which is appropriate to the child, to enable him or her to understand what is happening.

The Code and other legislation

The Code cannot be read in isolation from other legal rules. Rather, it recognises that a consumer's ability to consent may be subject to the provisions of other enactments. In addition to the qualification contained within right 7(1) itself, clause 5 states that the Code does not override other legislation and nothing in the Code requires a provider to act in a manner which would be a breach of any duty or obligation imposed by any enactment, or prevents a provider doing an act authorised by any enactment.

For example, providers need not obtain consent from either the child or the parent/guardian before performing services in emergency situations; or when administering a blood transfusion to a person under the age of 20, pursuant to s. 126B of the Health Act 1956.

4 Other Code rights

While this paper focuses primarily on the right of children to make informed choices and give informed consent, it is important to remember that children are entitled to all the rights in the Code whenever they receive health or disability services. The Code rights cannot be read in isolation. For this reason, I would like to briefly mention some of the other Code rights which also apply during the process of obtaining informed consent.

Respect – the 'Key to the Code'

Consumers are entitled to be treated with respect, to be free from discrimination, and to have services provided in a manner that respects their dignity and independence. The Commissioner has often spoken of the importance of these first three Code rights for consumers who are vulnerable, and commonly, elderly consumers in rest homes are referred to by way of example. However, consumers at the other end of the age spectrum, such as new-borns, infants and children who are not competent to consent for themselves are also particularly vulnerable and need to be shown particular consideration.

Right to support – Right 8

Every consumer has the right to have one or more support persons of his or her choice present. Depending on the circumstances, a child's support person or persons may also be those entitled to give consent on his or her behalf. In most cases the presence of support persons will not be an issue. It is only when safety may be compromised or another consumer's rights unreasonably infringed that the presence of a support person or persons may be denied. There may be situations where it would not be safe for a support person to remain with the child, for instance, in some situations involving surgery. The important thing to remember with regard to this qualification, as with the rest of the Code, is that the

individual circumstances of each case must always be considered and an attempt made to comply with the Code as much as possible in those circumstances – it is not an ‘all or nothing matter’.

Right to complain – Right 10

Providers can learn from consumers’ comments, complaints and suggestions and use them to improve the quality of service and care they offer. For this reason right 10 of the Code enables consumers to complain about the service they receive, in any form appropriate to them. This includes children, although in practice complaints about service provided to a child will often be made by the child’s parent or caregiver. Children and others who exercise their right to complain must be taken seriously and have their complaint dealt with appropriately.

Clause 3

Finally, providers will not be in breach of the Code if they can show they have taken all ‘reasonable actions in the circumstances’. The responsibility is on each provider to show this. If circumstances are difficult, the obligation as already pointed out is to take all reasonable steps to comply with the Code as much as possible in those circumstances.

5 Examples

Over the past two years since the Code’s inception the Commissioner has investigated a variety of matters where parents have complained on behalf of their child. These have included a pharmacist dispensing an incorrect prescription medicine to a child; a GP referring a matter involving a child’s broken leg to the Children, Young Persons and their Families Service; a podiatrist failing to obtain a parent’s informed consent before the removal of an ingrown toenail, and a hospital’s failure to provide full information to parents about a quarantined blood product administered to their son.

These examples involved situations where parents were present when their child was receiving a service. However, often health or disability services are provided to children at school, in the absence of parents, guardians or support persons. Dental services, vaccination programmes, hearing and eyesight tests, and even contraceptive advice and sex education classes are provided to children at school.

The Commissioner has often been asked to comment on the provision of services to children in this context. Her responses have emphasised the importance of obtaining informed consent before these services are provided. Where there are several components of the provision of service, such as with dental check-ups and treatment, the Commissioner has focused on the need for providers to obtain separate consent for each particular part of the treatment process – for instance, separate consent is required for both dental check-ups and x-rays. Further, the importance of keeping effective records such as immunisation certificates and written consent forms has been emphasised. Lastly, providers are encouraged to make adequate provision for communication with the children, by offering information appropriate to their level of understanding.

6 Conclusion

The provisions of the Code relating to informed consent are fundamental to the rights of all consumers, and the ability to make informed decisions is basic to the Code's cornerstone concept of individual dignity and respect. While the issue of consent in the case of children is complex and evolving, the provider who incorporates the principles of the Code of Rights into their protocols for obtaining informed consent can only improve their relationship with consumers, increase the effective utilisation of their service and reduce the chance of serious complaints.

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Commissioner's case notes

Crown Health Enterprise failed to obtain informed consent or provide all relevant information – Case Note 96HDC3240

The perceived increased risk to consumers of contracting Creutzfeldt-Jakob disease (CJD) from blood transfusions and blood products has led the Ministry of Health to make concerted efforts to ensure the public are informed of the benefits and risks of blood transfusions. It is likely that consumers who are at increased risk of contracting CJD from blood transfusions would expect to be informed of this risk. Such consumers must therefore be provided with realistic, accurate and understandable information so that they can make informed decisions about their treatment options.

One opinion by the Commissioner arose as a result of a complaint made by a consumer's parents against a CHE after the consumer, a minor, received a dose of Intragam from a batch of quarantined product. The product was issued by a technologist as if it were a nonquarantined product, and the consumer's parents had not given informed consent. The quarantined stock had been released with the approval of the Director-General of Health to be administered only with the informed consent of the recipient, as there was a possible link between the quarantined product and Creutzfeldt-Jakob disease. During a later visit to the Crown Health Enterprise by the child and its parents, a different technologist required specific informed consent before quarantined product was issued, which the parents refused. The earlier error was then discovered. The CHE notified the parents of the earlier issue of quarantined product and that it had been administered to their child without their informed consent.

The Commissioner found there was a breach of right 6(1)(b), right 6(1)(e) and right 7(1) of the Code. The parents had not been given information about the use of a quarantined product in their child's care. As neither the child nor its parents had been given information about the proposed use of the quarantined product, Right 6(1)(e) had been breached. Right 7(1) was also breached as a service had been provided without the informed consent of the parents who were entitled to give consent on their child's behalf.

Naturopath failed to provide all relevant information – Case Note 97HDC4036

One opinion by the Commissioner arose as a result of a complaint by a child's parents that a naturopath prescribed Ultrabifidus powder for their infant daughter which caused her to vomit and appear to lose consciousness. The child's parents had sought treatment for her eczema. They told the provider that the child had undergone bowel surgery two weeks after birth, that the child's mother was breast-feeding, and that the child had received her routine vaccinations. Following the provider's examination of the child and assessment of the information provided, the provider prescribed two homeobotanical products, a colic blend and bowel tonic. In addition the provider prescribed Ultrabifidus powder, a naturopathic remedy. The child was commenced on the homeobotanical products following the appointment, with no apparent problems.

The instructions on the Ultrabifidus Powder were to mix 1 ml of the powder with 100 ml of water. As this seemed a lot of liquid to give a baby on top of breastmilk, the child's father contacted the provider two days after the consultation, for advice on the administration of the powder. The provider advised the father to make a paste out of the powder and give it to the child on a spoon or dropper. The child was given the recommended dose via dropper at 7.30–8.00 pm. At approximately 10.30 pm the child vomited and appeared to lose consciousness. She was taken to hospital where she was admitted, and remained for observation for six days.

In the circumstances and in light of professional and other advice provided to the Commissioner, the Commissioner formed the opinion that the service provided by the naturopath met relevant professional standards and there had not been a breach of right 4(2). No information had been found to identify the precise cause of the events leading to the child's hospitalisation. It was also the Commissioner's opinion that right 6(1)(b) had not been breached. Given the nature of the products prescribed for the child, it was reasonable for the provider not to consider that any reaction may occur, and therefore not advise of any risks. However, in this case, a deviation from the usual instructions on the product label was required due to the child's age and feeding requirements. It was reasonable for the child's parents to receive directly from the provider the information required to administer the products. Therefore, the Commissioner found a breach of right 6(1)(e).

The Commissioner suggested that the provider consider all aspects of an infant's requirements when prescribing any naturopathic or homeopathic therapy. In this case, as the baby had undergone major bowel surgery, the provider could have considered discussing the information with the family's medical practitioner. The Commissioner also recommended that the provider ensure consumers are given clear information at consultations on how to administer prescribed products so consumers are not solely reliant on the product labels.

Podiatrist failed to seek informed consent or consider treatment options – Case Note 96HDC1423

One opinion by the Commissioner arose as a result of a complaint made about a podiatrist by the parent of a child, whose ingrown toenail was treated without either the child or the

parent being fully informed and without their prior consent being obtained. The podiatrist treated the ingrown nail by removing it and destroying the nail root to prevent further re-growth. Neither the child nor parent were informed that the consequence of this procedure was permanent as the nail would not grow back. The Commissioner found the podiatrist in breach of the following Code rights.

Right 4(2) was breached as the podiatrist did not provide services that met professional standards. There may have been other treatment options available, but the podiatrist did not consider them. The consequences of the procedure were not considered or discussed, nor was any offer to seek a second opinion made.

Right 6(1) was breached as the podiatrist did not fully inform the child or parent of the proposed procedure, its consequences, or the other options available and the risks, benefits and costs of each option.

Right 7(1) of the Code was breached as neither parent nor child had made an informed choice about, or given informed consent to, the procedure before it was performed.

Disclosing children's health information: A legal and ethical framework

Sarah Kerkin

Executive Officer, Privacy Commissioner, Te Mana Matapeno Matatapu

Introduction

Disclosing information about patients raises privacy issues under the Health Information Privacy Code 1994 and broader issues of confidentiality derived from health professionals' ethical duties. At first glance, the issues can seem very complex but if the various elements are separated and considered individually, it is much easier to both identify and follow the duties.

The issues of privacy and confidentiality are thrown into sharp relief when dealing with patients who are children. On the one hand, the professional's primary ethical duty is to the patient. On the other, the professional is dealing with a patient who may be well under the legal age of consent and who may or may not be competent (in terms of understanding to consent to treatment). The professional may also have to deal with anxious parents or guardians who, not unnaturally, want to know about the situation. Balancing these competing interests is not easy and has, in the past, come down to professionals exercising their judgement based on clinical and ethical issues. The law has tended to mirror this approach. The Privacy Act 1993 has not substantially changed it, as I shall explain.

So how does the Privacy Act – or the Health Information Privacy Code 1994, which applies in respect of health information and health professionals – address these issues?

Parents do not have an automatic right to information about their children. As with other rights-based legislation in New Zealand, the Privacy Act and the Code draw no real distinction between their application to children and to adults. This is not a novel concept. Confidentiality of information about children – particularly with older children – has long posed difficult issues for health professionals, just as consent to treatment has posed difficult issues. The Privacy Act only adopts existing notions that children have a degree of autonomy which does not rely on a particular age.

The tension between parents' rights and children's rights can pose problems for health professionals who want or need to disclose information to parents to enable the parents to give informed consent to treatment. Although the law seems confusing, the tensions can be identified through outlining the framework of ethics and law which overlay privacy and confidentiality.

In my experience, privacy law is sufficiently flexible to meet most, if not all, situations involving patient information. Clinical and therapeutic issues are little affected by the law, and they pose the most difficult problems. The balance between retaining a patient's trust

and fulfilling functions as health professionals is very delicate indeed, particularly when the patient's wishes and the professional's opinion are at odds.

Age, consent and information

It is not within the scope of this paper to summarise the law of informed consent as it relates to children. Nor should it be assumed that the law will translate well into a privacy context. But there are some similarities.

There are numerous cases, in New Zealand and overseas, about the treatment of children and whether competence to consent should be determined by age or capacity.⁴ *Gillick v West Norfolk and Wisbech Area Health Authority*⁵ adopted an understanding-based approach: children acquire capacity to have lawful dealings in cases of medical treatment within their minority, provided they have the requisite understanding and maturity to enter the transaction. This will be a question of fact in each case.⁶

To some extent that approach has been mirrored in New Zealand through the Code of Health and Disability Services Consumers' Rights, which does not adopt an age test. Instead, it provides that consumers with diminished competence retain the right to give informed consent to the extent appropriate to their level of competence.⁷

The application of an understanding-based test is more complex and requires more careful judgement than does a status-based test, which ignores the fact that children are often autonomous, intelligent beings before their 16th birthdays.

In view of the apparent willingness of the law and clinicians to listen to the views of mature minors, the Privacy Commissioner did not consider that fixing a particular age in the Code would be particularly helpful. The Code has essentially adopted an understanding-based test for the ability to exercise rights under it.

If you would be prepared to listen to the views of a mature minor in respect of treatment, you should do the same with respect to his or her personal information, the implications of which I shall explain later.

Privacy, confidentiality and trust

It is hard to over-emphasise the importance of trust in the therapeutic relationship. Patients often have to divulge sensitive personal information in order to obtain treatment. Children – particularly older children – may not want their parents to know this information. They

⁴ For a good discussion on this issue see McDowell, 1997. Medical treatment in children: assessing the scope of a child's capacity to consent or refuse to consent in New Zealand. *JLM* 5(1): 81.

⁵(1986) 1 AC 150.

⁶ See McDowell 1997 (refer Note 4) page 87.

⁷ Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations 1996, right 7(3).

may find it difficult to confide in anyone, even (or perhaps especially) health professionals. They will do so only if they can trust the health professional not to judge and not to breach their confidences.

Health professionals need patients' co-operation and information to treat effectively, and must win their trust before patients will confide in them. Privacy and confidentiality are the means by which health professionals gain their patients' trust. Assurances of confidence and discretion tell patients that it is safe to confide in professionals, that their secrets will not be divulged. They tell patients that professionals respect their autonomy, dignity and sensitivity. This is the key to gaining trust because it allows those first steps towards building a relationship to be taken. It is no different for children – particularly older children – than for adults.

If patient expectations of confidence are not met and patients do not feel respected, this trust will never grow. The therapeutic relationship may never develop to a point where patients have faith in professionals, so professionals cannot be confident in patients' candour. This is important, because professionals rely on patients' information and reporting to a certain extent in making a diagnosis. If patients do not trust professionals sufficiently to be candid, there will be serious implications for the professional's ability to treat them effectively. This may in turn, have serious implications for the patient's overall health and for the efficient allocation of health resources.

All of these issues need to be weighed in deciding whether or not to disclose information, quite apart from what the law requires. These issues provide the basis for the framework of law and ethics which regulates the disclosure of patient information. This framework contains a number of elements, which can be broken into two broad categories: anticipated disclosures and unanticipated disclosures.

Anticipated disclosures

Anticipated disclosures are the disclosures most easily addressed. They occur when the need to disclose has been anticipated at the point of obtaining the information: the intention to disclose has existed from the start.

There are two key concepts in the Health Information Privacy Code 1994:

- purpose
- openness.

Anticipated disclosures tend to accord fairly closely with these concepts. Rule 11 of the Code allows information to be disclosed if the disclosure was one of the purposes for which the information was obtained in the first place.

If the information to be disclosed was collected directly from the patient or a representative, they would normally have been informed of the purpose at that stage in

accordance with the principle of openness.⁸ The Code does not require consent to be obtained for these anticipated disclosures: it is purpose-driven, not consent-driven.

Purpose and openness have a number of advantages, not the least of which is that if information policies are established and patients are alerted to them, agencies are less likely to breach the Code. They are also less likely to receive complaints, because people tend to complain about disclosures when they are unpleasantly surprised to find that they have occurred.

There are two further advantages:

1. The patient understands the purpose and has the opportunity to express any concerns with the intended disclosure. Although the Code does not require patients to consent to a disclosure when that is a purpose for obtaining the information, some ethical obligations might require consent, so this provides an opportunity to obtain it.
2. The purpose is clearly established before the disclosure is made, providing a clear response to a complaint made to the Privacy Commissioner.

So if anticipated disclosures mean the purpose for collecting the information has been established, what are the purposes for obtaining health information? One of the purposes for obtaining information about a patient's health is to provide appropriate treatment. Given that obtaining informed consent is an integral part of providing treatment, it seems clear that one of the purposes for which health information is collected is to give patients sufficient information for them to grant informed consent for treatment.

If the person who is to receive treatment does not have the capacity to consent to it, then consent needs to be sought from another, appropriate, person. That person, too, needs sufficient information in order to grant informed consent. Thus, health professionals are in a strong position to argue that, when collecting information to treat a child whose parents or guardians will be asked to grant consent, one of the purposes for obtaining the information is to disclose sufficient information to the parents or guardians for them to grant consent.

When treating children, there will always be an issue about who should consent to the treatment. The issues are perhaps more easily resolved for very young children than for older children or mature minors, who may well have their own views on what is appropriate for them. Health professionals prepared to consider a mature minor's views on

⁸ Rule 2(2)(b) provides that information does not have to be collected from the individual concerned where the agency believes on reasonable grounds that the individual is unable to give his or her authority and, having made the individual's representative aware of the matters set out in subrule 3(t), the health agency collects the information from the representative or the representative authorises collection from someone else.

Rule 3(l) requires health agencies to take reasonable steps to make individuals aware of a number of matters when information is collected directly from them. Those matters include: the fact of collection; purpose; intended recipients; contact details for the agency (or agencies) collecting and holding information, whether supplying the information is voluntary or mandatory; consequences of not providing the information and the individual's right of access and correction.

treatment should also take account of his or her views on privacy and confidentiality. Therefore, when information is collected from the mature minor, he or she should be made aware of the matters required by rule 3, just an adult would be.⁹ This would include advising that some information will be disclosed to the parents if the parents are to be asked to give informed consent.

Facilitating informed consent does not necessarily involve disclosing the child's entire medical records. It means disclosing that information which is necessary to enable the parents to grant informed consent. Right 6 of the Code of Health and Disability Services Consumer's Rights may provide a good guide as to the information that a reasonable consumer would expect to receive:

- (a) an explanation of his or her condition; and
- (b) an explanation of the options available, including an assessment of the expected risks, side effects, benefits and costs of each option; and
- (c) advice of the estimated time within which the services will be provided, and
- (d) notification of any proposed participation in teaching or research, including whether the research requires and has received ethical approval; and
- (e) any other information required by legal, professional, ethical, and other relevant standards; and
- (f) the results of tests; and
- (g) the results of procedures.

If this kind of information would normally be disclosed to facilitate informed consent, that would seem to be a purpose for obtaining the information. So disclosure to the parent being asked to give informed consent to treatment of a child would seem to be allowed by the Code.

Unanticipated disclosures

The more difficult problems arise when the need for disclosure has not been anticipated, so it is not one of the purposes for which the information was obtained. This is often where health professionals make the mistake of heading straight to rule 11 of the Code and assuming the disclosure cannot be made. In fact, there are a number of laws which apply to personal information and they may need to be considered.

The Privacy Act and Code do not detract from any law which authorises or requires information to be made available.¹⁰ So where there is such a law, it should be followed. The distinction between laws authorising and requiring disclosure is important. If a statute requires disclosure, the disclosure must be made. It will not breach the Health Information Privacy Code. The New Zealand Medical Association's code of ethics allows disclosures which are required by law. It would be very surprising if other professional bodies would

⁹ Ibid.

¹⁰ This means any Act of Parliament and any regulations issued pursuant to an Act.

be prepared to find someone guilty of a breach of ethics through making a disclosure which was required by law.

If a statute merely authorises disclosure, health professionals are left with a discretion: they can choose not to disclose. While disclosure in accordance with such a law will not breach the Code, some codes of ethics will not allow it so the disclosure may well breach ethical duties.

It is therefore important to be very clear about whether the disclosure is required or only authorised. Words like 'shall' indicate that the disclosure is required, 'may' indicates that the professional has a discretion.

There are two statutory provisions which are relevant to the issue of disclosing children's health information to parents.

Code of Health and Disability Services Consumers' Rights

The Code of Health and Disability Services Consumers' Rights is a law, because it is contained in statutory regulations. Therefore, if it requires or authorises the disclosure of personal information, that will not be overridden by the Health Information Privacy Code.

The Code contains a number of provisions which are relevant to the issue of informed consent. As already noted, individuals with diminished competence have the right to give informed consent to the extent appropriate to their level of competence.

Right 6(1) gives consumers the right to certain information. Right 6(2) provides that before giving consent, every consumer has the right to the information that a reasonable consumer, in that consumer's circumstances, needs in order to give informed consent. Right 7(1) provides that services may be provided only if the consumer has given informed consent, except where other enactments, the common law or the Code of Health and Disability Services Consumers' Rights provides otherwise.

'Consumer' is defined to include a person entitled to give consent on behalf of the consumer. Section 25 of the Guardianship Act 1968 provides that guardians may give consent to a medical, surgical or dental procedures where that is necessary or sufficient. Guardians may therefore be asked to give informed consent to treatment of a child under 16, although it should be remembered that children seem to have a right to give informed consent to the level of their competence.

Where a guardian is asked to give consent, the guardian would seem to be a consumer for the purposes of the Code of Health and Disability Services Consumers' Rights, and has the right to certain information before giving consent. Therefore, the guardian seems to have a right to the information set out in right 6(1). There is, then, a corresponding obligation on health professionals to provide that information to the guardian. It could thus be argued that the disclosure is required by law. That disclosure would not be overridden by the Health Information Privacy Code.

Health Act 1956, section 22F

Section 22F requires information to be disclosed to representatives on request, although it does set out some withholding grounds which may be relied upon to withhold the information. ‘Representative’ is defined in the Health Act 1956 and, in relation to a child under 16, is that child’s parent or guardian.

Requests by representatives can be refused only if:

- there is a lawful excuse not to disclose
- refusal is authorised by a code of practice issued under the Privacy Act 1993.

Rule 11(4) of the Health Information Privacy Code authorises the refusal of a representative’s request if:

- i. the disclosure of the information would be contrary to the individual’s interests; or
- ii. the agency has reasonable grounds for believing that the individual does not or would not wish the information to be disclosed; or
- iii. there would be good grounds for withholding the information under Part IV of the [Privacy] Act if the request had been made by the individual concerned.

If the withholding grounds do not apply, the information must be disclosed. If the withholding grounds do apply, the information may still be disclosed because reliance on the withholding grounds is discretionary.

Essentially, the withholding grounds allow health professionals to exercise their judgement. In deciding whether to rely on the withholding grounds when dealing with requests by parents who will be asked to consent to procedures, it is important to remember that they may need the information in order to grant informed consent.

Health Information Privacy Code 1994, rule 11

If there is no statute authorising or requiring the disclosure of health information, health professionals must consider:

1. whether they want to disclose (as there is no obligation to disclose except where required by law)
2. whether any of the exceptions in rule 11 would allow the disclosure.

There are a number of exceptions which might apply in this context.

Rule 11(1)(a)(ii)

The disclosure is to the individual’s representative where the individual is dead or unable to exercise his or her rights.

- In relation to children under 16, a parent or guardian is a representative.¹¹
- It should not be assumed a the child cannot exercise his or her rights simply because of his or her age. Understanding and maturity are relevant to the ability to exercise rights.

Rule 11(1)(b)

The disclosure is authorised by the individual or the individual's representative where the individual is dead or unable to give his or her authority.

- If the disclosure has not previously been discussed with the individual, he or she could be asked to authorise it.
- It should not be assumed that a child cannot grant an authorisation simply because of his or her age. Again, understanding and maturity will be relevant.

Rule 11(1)(c)

Disclosure is one of the purposes in connection with which the information was obtained.

- This has already been canvassed.¹²

If it is not desirable or not practicable to obtain the patient's authorisation other exceptions are available. It will not be practicable or desirable to obtain an authorisation if the patient is:

- unconscious
- not competent (although age alone does not necessarily determine competency)
- has refused to give authorisation.

Rule 11(2)(b)

The information is disclosed by a registered health professional to a person nominated by the individual concerned or to the principal caregiver or a near relative of the individual concerned in accordance with recognised professional practice and the disclosure is not contrary to the individual's or representative's expressed request.

- This seems particularly applicable to situations involving young children who would not be competent to give an authorisation and where recognised professional practice would be to deal with the parents or guardians.

¹¹ The Code adopted the definition of 'representatives' used in the Health Act 1956.

¹² See Anticipated Disclosures.

Rule 11(2)(d)

That the disclosure is necessary to prevent a serious or lessen a serious imminent threat to the life or health of the individual concerned.

- For instance, if the disclosure to a representative was necessary to obtain consent for an emergency procedure.¹³

Disclosure under rule 11 is discretionary. Health professionals cannot be required to disclose simply because one of the exceptions applies. Disclosure in accordance with rule 11 may not be allowed by some codes of ethics, so health professionals should check their ethical duties before relying on an exception in rule 11.

Conclusion

The information issues underlying informed consent are less complex than the wider issue of informed consent and children. Although there are a number of approaches to the issue, the result seems to be the same: informed consent involves the disclosure of a certain amount of information to the person giving consent. The law seems to be sufficiently flexible to allow that.

The approach which most closely accords with the notions of autonomy and dignity central to the Health Information Privacy Code and the notions of trust and respect central to good clinical practice, is that of the anticipated disclosure. Agencies can – and should – establish information handling policies which are based on purpose and openness. When dealing with mature minors, be open with them if parents' consent to treatment will be sought: tell them that a certain amount of information will have to be disclosed in order to obtain their parents' consent. Try to be sufficiently flexible to accommodate their concerns. That way, health professionals will comply with the law and ethical codes, while upholding the trust, so fundamental to the therapeutic relationship.

Sarah Kerkin
Office of the Privacy Commissioner
PO Box 466
AUCKLAND

privacy@iprolink.co.nz

Tel 09 302 8680
Fax 09 302 2305

¹³ Although the need for informed consent can be waived in emergencies. See McDowell 1997 (refer Note 4), page 83.