

Informed Consent

Legislative Base:

There are a number of Acts of Parliament and one set of regulations that set out the provisions that apply in giving consent.

The following apply to all health and disability service providers:

- **The Health and Disability Commissioners Act 1994**
- **The Health and Disability Commissioner (Code of Health and Disability Services Consumers Rights) Regulations 1996**
- **The New Zealand Bill of Rights Act, 1990**
- **The Human Rights Act, 1993**

Some of the others that may apply to your service are:

- The Guardianship Act 1968
- The Protection of Personal and Property Rights Act 1988 (3PR)
- The Mental Health (Compulsory Assessment and Treatment) Act, 1992
- The Criminal Justice Act, 1985
- The Children, Young Persons and their Families Act, 1989
- Contraception, Sterilisation and Abortion Act, 1977
- Alcoholism and Drug Addiction Act, 1996
- Health Act, 1956
- Crimes Act, 1961
- Privacy Act, 1993 and the Health Information Privacy Code, 1994

The information below is a brief outline of some of the other legislation.

As a provider, you will need to decide which of the other acts are relevant to the service you provide. If this applies to your service you need to carefully consider how it might affect the service you provide and seek advice where needed.

Guardianship Act

Where consent on behalf of a child is necessary that consent can be given in the first instance by the child's guardian (s.25 (3)). If the guardian cannot be found or is incapable of giving consent then the person acting in the place of the parent may give consent (in loco parentis) (s.25 (3) (b)). If there is no-one acting in the role of guardian then a District Court Judge or the Chief Executive of the health provider may give consent (c).

S.9 of the Act allows the High Court or a 'duly appointed agent' of the High Court to give consent to any form of medical treatment or procedure that is in the child's welfare.

In emergency situations, treatment can be given without consent.

If parents refuse consent and the medical view is that the proposed treatment is in the best interests of the child or young person, a court order may be sought. Under such an order the court assumes guardianship of the child to ensure he/she receives the appropriate treatment.

Where guardianship has been vested in the court the power to give or withhold informed consent rests with the court or its agent.

Under the Guardianship Act children over the age of 16 can give consent to any medical, dental or surgical procedure, so long as they are able to understand the nature and consequences of such treatment.

Guardianship begins when the child is born and ends at age 20, regardless of the ability of the individual.

Mental Health (Compulsory Assessment and Treatment) Act

A person can lose the right to give consent to certain aspects of their life and be required to undergo psychiatric assessment and treatment. A set process must be gone through before compulsory assessment and treatment may be carried out. Such orders for assessment and for treatment have different timeframes some of which are able to be extended by the court. Written consent from the patient may be required for further treatment after a suitable period of treatment and for some specialised treatments and surgery.

The Criminal Justice Act

Under s.121 the court can order a psychiatric report without consent if it would assist the court in determining whether the defendant is “under disability” or insane (under s.23 Crimes Act). It may also be used to determine an appropriate type and length of sentence or any conditions or requirements the court may impose as part of that sentence or order.

The Children, Young Persons and Their Families Act

The Court may require a child or young person to have a medical examination by a registered doctor if there are reasonable grounds to suspect the child or young person has been subjected to ill treatment, abuse, neglect, deprivation or serious harm. (s.49-52). The court can also order medical, psychiatric or psychological examination for the purpose of the court’s proceedings. In certain circumstances a social worker may also require the child or young person to be examined by a registered doctor.

Where the Director-General of Social Welfare has been appointed as sole guardian of the child, then informed consent can only be given by the Director-General. Additional guardians appointed under this section may give informed consent on behalf of the child or young person. (s.110).

Caregivers appointed under s. 139 – 142 may be given the power to consent on behalf of the child or young person as part of the agreement placing that child or young person in their care. (s.149). Be aware that caregivers do not automatically become the guardians of the children or young people they care for, nor are they automatically granted the right to give informed consent on behalf of the child or young person in their care.

The Protection of Personal and Property Rights Act

The 3PR Act allows for the appointment of a Welfare Guardian, a Property Manager, an Enduring Power of Attorney or for Personal Orders. It sets out to protect the rights of people who through disability, age or illness are not fully able to manage their own affairs. It applies to people over the age of 20 (or those over 16 who are married, or have been married) who EITHER

- Lack, partly or fully, the capacity to understand the nature of decisions about their own personal care and welfare, and the capacity to foresee the consequences of such decisions;

OR

- Have these capacities, but be fully lacking in the capacity to communicate decisions about their personal care and welfare.

Under the 3PR Act a person is presumed to be competent until it is proven otherwise. Simple labels such as having an intellectual disability are not reason enough to make Personal or

Property Orders or appoint a welfare guardian. Any such orders will outline what areas of personal care and welfare may be covered.

A welfare guardian or enduring power of attorney may not refuse consent for standard medical treatment or procedures intended to save the life or to prevent serious damage to the person's health. Neither may they give consent to electro-convulsive (ECT) treatment; brain surgery or brain treatment designed to alter behaviour or to taking part in medical experiments unless the experiment is necessary to save the person's life.

Where there is no enduring power of attorney or welfare guardian and an individual lacks the capacity to manage their own affairs the court has the power to make Personal Orders. There are eleven different types of personal orders. Any personal order granted by the court will be very specific to the person and situation.

An enduring power of attorney allows a 'donor' to appoint an 'attorney' to make decisions on their behalf when the donor becomes incapable. Such decisions may be general or specific and may relate to personal care and/or welfare or to property. A donor must be 'competent' in order to appoint an enduring power of attorney.

An enduring power of attorney for property may not give consent for personal care and welfare.

An enduring power of attorney is subject to the same restrictions as a welfare guardian.

With the exception of an enduring power of attorney, all other orders granted under the 3PR Act are for a set period of time specified in the order.

Contraception, Sterilisation and Abortion Act

S. 4 allows a parent, guardian or a person who has custody of a "mentally subnormal" female (as defined by the act) to administer contraception if it is considered in the woman's 'best interests'.

Under s.7 no one has the power to consent to the sterilisation of another person just because the person is considered too young to consent on their own behalf.

New Zealand Bill of Rights Act

Under s.8 no person may be deprived of life except on such grounds as are established by law and are consistent with the principles of fundamental justice. S. 9 provides that no one shall be subjected to torture or to cruel, degrading or disproportionately severe treatment or punishment. Under s. 10 and 11 every person has the right not to be subjected to medical or scientific experimentation without their consent; and to have the right to refuse medical treatment.

Just because a section of law excludes someone from giving informed consent, there is no corresponding section of law that removes the right of the individual to communication and information about the proposed action. The individual should always be given an explanation of the proposed treatment or action in enough detail and in a way that he/she is able to understand the purpose behind the action as well as any benefits or possible risks.

The Code of Health and Disability Services Consumers' Rights

Copies of The Code should be available in offices of all disability support service providers, doctors' surgeries, Hospitals, Libraries or from the Health and Disability Commission Offices.

The Code applies to all health services and disability support services within New Zealand. It places obligations on all people and all organizations providing services, and gives rights to all consumers using those services. It applies to any sort of health or disability service, whether public or private. It applies to research and teaching as well as service provision.

What is consent?

Consent may be defined as 'granting to someone permission to do something they would not have the right to do without such permission.'

Informed consent implies that enough relevant information is provided to enable a reasoned decision to be made, and that information was understood. Without understanding what is involved no one can make a reasoned decision.

The consent must be voluntary. There should not be any pressure on the person to give their consent. No undue influence or duress should be present.

(New Zealand Health Council Working Party on Informed Consent, 1989)

What's needed for informed consent to be correct?

Under the Code no health care procedure or disability service may be carried out without informed consent, except where law permits it.

Right 7 of the Code sets in place the provision to make an informed choice and to give informed consent. The giving of consent is a process that involves:

- Enough information to make a decision
- The information is understood
- The person is competent to decide
- A decision is made without pressure or coercion

For many situations verbal consent will be sufficient. However, consent must be in writing if:

- The service user is to participate in any teaching or research; or
- The procedure or action to be undertaken is experimental; or
- There is considerable risk of adverse effects on the individual; or
- The individual will be under general anaesthetic
- The service user under Mental Health (CAT) Act. Written consent is needed to treatment after the first month of the compulsory treatment order; for electro-convulsive treatment and to brain surgery.

It would be prudent to identify situations within your organization where written consent will be sought eg decisions that have a major impact on the life of a service user (eg moving residential placement, Lifestyle planning).

Each individual in your service may arrive at a consent decision in a different way. Those people most familiar with the service user should be involved in recording the most suitable

process whereby that individual gives consent. This process should be reviewed on a regular basis and at least annually.

Information Required for Consent

Right 5 of the Code provides for effective communication in a “form, language and manner that enables the consumer to understand the information provided”.

This may mean that support staff need to present the information using plain language, pictures, symbols, role plays, or models. This may need to happen on a number of different occasions over a period of time in order for the service user to understand what is going to happen. All questions the service user asks must be answered honestly and accurately. A written summary of the information may be requested.

Right 6 of the Code, outlines the information the individual should expect to receive, before making any decisions. Although it lists an explanation of his or her condition as one of the basics required, the giving of information is not limited to health procedures only, but applies to all health and disability services.

For routine / general decisions:

- The choices available
- What can happen for each of those choices
- The timeframe
- The end result / outcome

Health Treatment or Medical Procedures:

- An explanation of his/her condition
 - An explanation of options available (including risks, side effects, benefits, outcomes, costs of each option) i.e. what is going to happen, how it is going to happen, any risks in both having and not having the treatment and likely outcome.
 - An estimate of the timeframe within which the treatment/services will be provided
 - The results of tests and or procedures
 - Notification of any proposed participation in teaching or research
 - Any other information required by legal, professional, ethical and other relevant standards
- Any questions you may have must be answered honestly and accurately. You may request a written summary of the information provided.

Most intellectual disability service providers do not normally provide medical treatment. This is usually provided by a health professional, eg a G.P., hospital, specialist, dentist, etc. However support staff may be providing support to service users at health related visits.

Competency to Consent

Under the Code, everyone is presumed competent to make an informed choice and give informed consent, unless there are reasonable grounds for believing the person is not competent.

Where a service user is not competent, they retain the right to make informed choices and give informed consent to the extent appropriate to his or her level of competence.

Just because someone has an intellectual disability, it does not mean they are not competent to give consent. It may require a change of language, visual presentation of information, or several explanations given over a period of time, for the individual to understand and give consent.

Ideally, people with an intellectual disability should have a support person with them when they are considering a health or disability service. This person can be a family member, caregiver / staff member, friend, advocate, or some other person who knows the person well. The support person will know how to paraphrase and present information in a way that will help the individual to understand.

People with an intellectual disability may be able to give consent for some things but not for others. Depending on what is being proposed, there will be graduated levels of consent. Eg they may understand about friendship, but not what is involved in a sexual relationship.

Court orders particular to that decision may over-ride the ability of the individual to give or refuse consent. Any such orders should be on the individual's file with details of delegated authority noted. These may be orders under Mental Health (CAT) or could be orders under the 3PR Act (eg Personal order). Any such order would specify who would give consent.

A service user cannot give consent if:-

- They are unconscious
- They are a child under the age of 16
- They are a young person between 16 –20, and they do not understand the nature and effect of the treatment
- They are over 20 and they are unable to understand the nature and effect of treatment.

Advance Directives

Advance directives can be used to allow an individual to make choices about possible health procedures or disability services and can transfer the right of consent to a named individual. Such directives are intended to be effective **only** when the individual is no longer competent and should spell out what areas of care and / or welfare are covered.

These are usually formalised through an Enduring Power of Attorney under the 3 PR Act. Hospitals may also record advance directives on a patient's notes that may not be formalised through an Enduring Power of Attorney.

Advance directives can only be given if the individual is competent at the time of giving the directive. They are not intended to be used as a way to bypass the consent giving process for a person with an intellectual disability because someone else is having difficulty meeting timeframes for consent.

Determining 'capacity'

Many people may be considered unable to give consent if presented with a lot of jargon and /or complicated medical language. In these situations most people ask for a 'translation'. The same must occur for people with intellectual disabilities. Information about any health care procedure or disability service is expected to be given in 'a form, language, and manner that enables the consumer to understand the information provided.' (Right 5).

If the service user is able to give a simple explanation of what is to occur, then they may be considered competent. Eg if they were able to say that they were going into hospital to have an operation to fix their eye, they were going to be asleep when it happened and the doctor was going to put in a new bit so that they could see clearly when they woke up, they could

give consent for a cataract operation; or if they were able to say that they were going to be moving house (or didn't want to move house!) from where they now live to a new named address and would be living with other named people in the new house, as well as when that move was to happen and some of the staff who might be supporting them in the new home, they could be said to consent (or not consent).

Not Competent to consent

Remember that everyone is thought to be able to give consent unless it is proved otherwise. (Right 7 (2))

Where a person is considered incompetent, that person still keeps the right to make informed choices and give informed consent, to the extent appropriate to his or her level of competence. (Right 7 (3))

It is important that people with an intellectual disability are not denied treatment or services because of a perceived difficulty in gaining consent.

The only times there is authority for people to give consent for someone else are:

- When it is a child under the age of 16 years (there are some situations children under 16 may give consent). The child's parents (or an appointed legal guardian) will give consent for the service or procedures.
- A young person between 16-20, if they do not understand the nature and effect of treatment. The young person's parents or legal guardians will give consent.
- When there is an Enduring Power of Attorney that is now in operation.
- When there is a Welfare Guardian appointed, or a Personal Order made under the Protection of Personal and Property Rights Act 1988.
- When there is an order made under the Guardianship Act 1968.
- When there is an order made by the High Court exercising *Parens Patriae*.
- Where there are any other Court Orders relating to placement, care and treatment under relevant legislation, (eg Mental Health (Compulsory Assessment and Treatment) Act, Criminal Justice Act, Guardianship Act). Copies of any orders should be kept on the service user's file.

Families do not automatically retain guardianship of adults with disabilities once they reach 20. This means they may give advice, but cannot legally give consent on behalf of the service user.

Right 7 of the Code presents a guide on what to do when a person is not capable of giving consent.

Where a service user is not able to give informed consent and there is no other person available who is legally entitled or authorised to give consent on behalf of the service user then the provider of the service or treatment can go ahead and give the service or treatment if:

- (a) It is in the best interests of the service user; **and**
- (b) An attempt has been made to find out what the service user thinks about the what is being suggested; **and**
- (c) The provider thinks that this is what the service user would agree to if they were able to give consent; **or**

- (d) If the provider of the service or treatment hasn't been able to find out what the service user would do, then they may talk to other people who know the service user well and are interested in the welfare of the person. These people might be staff, family, friends or an advocate. They may offer advice to the provider but do not give consent.

This does not mean that a person can give consent on behalf of another person. It just means that the provider is aware of other peoples' views about a particular service/treatment and can go ahead and give a service or treatment.

For specific medical / dental treatment where there is someone legally entitled to give consent on behalf of the service user, then they must be the person to sign the consent form. Some service providers and some hospitals may have their own formal in-house process that can be used where the service user is unable to give consent.

If the service user is incapable of giving consent, the law clearly lays the duty of decision on the medical practitioner. The provider has the **authority** and the **responsibility** to go ahead and give the treatment, or not. That person is entitled to consult others, but ultimately must make the decision to provide treatment, procedures or services; or to apply to the Court for consent.

If non standard or non-therapeutic procedures are being considered, then the legal protection of the Protection of Personal and Property Rights Act and the Family Court may be sought. The resulting order can be either:

- A Welfare Guardian Order; or
- An order that a person be provided with medical advice or treatment of a particular specified kind. (Personal Order)

It is up to the medical professional to seek the court order if it is considered necessary.

There is a need to maintain accurate records to demonstrate the process used to reach the decision made on behalf of the service user. This will include information given, format of information, when the information was given, who gave the information, an indication of what the individual understood, what advice might have been sought and who eventually gave consent.

Emergency Action

Emergency action, required for preserving the health and wellbeing or the saving of life, in serious injury or illness can be provided without consent. Only treatment that is necessary for the service user's immediate well-being can be carried out without consent.

If the individual is able to give consent at the time then they may consent or refuse the emergency treatment.

Emergency action for serious injury or illness **is the duty of the provider.**

Right to refuse treatment or services

Under both the Code (Right 7 (7)) and the Bill of Rights Act (s. 11), everyone has the right to refuse to undergo any medical treatment or service.

Because the person has an intellectual disability it does not automatically mean that they are not competent to consent or refuse the proposed treatment or service. The individual must be assessed to decide whether or not he or she understands the proposed service / treatment and the consequences of refusing it. Staff need to check why the refusal has happened. It may be that the service user is afraid, unsure of what is to happen, doesn't like what is offered (eg an injection). Staff may need to provide the information in another way to help the service user understand and provide support to work through the issue.

If the service user understands the consequences of refusing services and treatment they are entitled to refuse the service or treatment and their refusal cannot be overruled either by staff or family members. (Check for Court Orders that may over-ride the refusal).

Where the individual does not have capacity to refuse the treatment, then the provider may provide the service or treatment to the individual that is in his or her best interests, as would be agreed to by a reasonable body of medical opinion or the professional body's code of ethics. If there are serious doubts about the individual's capacity to refuse treatment or service, then the provider has the option to seek an order from the Court before carrying out the proposed treatment or service.

Participation in teaching and research

Whenever service users are involved in teaching or research, written consent is needed. This includes the service user being directly involved as a participant in the research or teaching as well as situations where the staff are undergoing training, or undertaking further study or research as part of a training course. This training may be internal or external to the service they work in. Consent of the service user must be gained before they take part and before using any information about the service user in units or assignments. (Privacy Act considerations dictate that the service user give permission before personal information is used, where the information that has been collected as part of service provision is to be used for a different purpose).

Service users have the right to refuse to participate in any teaching or research.

Policy Writing

This is not a complete list, rather some ideas to get you started on writing your own policies. These policies do not need to be complicated or many pages in length, but should include the basics – what does it mean, what's needed and what to do.

Each provider will need to decide

- What is appropriate for their own organization or service
- Which legislation is relevant to their organization or service
- Who the policy is for (staff? Families? Service users? All of the above?) –This will dictate the format of the policy, the language to be used, etc
- Which situations are appropriate to the service and setting as outlined in Standard 1.8 (eg storage, disposal and return of body parts probably doesn't apply to intellectual disability residential services)
- What special cultural considerations are required to be included and how this might happen
- Which definitions need to be included so all members of the organization are clear about meanings.
- What processes your organization will follow to gain consent and how that process will be recorded.

- Which situations would require written consent and when verbal consent will be sufficient.
- What documentation needs to be developed, eg do you need to develop a consent form for staff to use in training situations?
- What records require to be kept, how often they will be reviewed and where they should be kept.
- What training/ongoing education is needed for staff, families and service users
- How often the policy, training and consent processes will be reviewed.

Who to contact:

- Your own agency policy or guidelines if already developed.
- Other experienced providers
- Your organization's legal adviser – do remember that their legal expertise may be in other areas
- Office of the Health and Disability Commissioner
- Legal risks advisers at your local DHB
- EQS

Where to find information:

Legislation is available on the web – www.legislation.govt.nz or can be bought from Bennetts Bookshops

Office of the Health and Disability Commissioner, P.O. Box 1791, Auckland. Ph (09) 373 1060, 0800 11 22 33. website www.hdc.org.nz

Consent in Child and Youth Health; Information for Practitioners, available from the ministry of Health or their website www.moh.govt.nz

Health and Disability Sector Standards available for purchase from Standards New Zealand, Private Bag 2439, Wellington

References:

The Guardianship Act, 1968

The Health and Disability Commissioner's Act 1994.

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

The Human Rights Act, 1993

The Protection of Personal and Property Rights Act, 1988

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September 2003

Standard 1.8: Informed Consent

Consumers'/kiritaki consent is obtained in line with the requirements of the Code of Health and Disability Services Consumers' Rights 1996.

Criteria: The criteria required to achieve this outcome include the organization ensuring:

1.8.1: The service has implemented policies and procedures that comply with the requirements of the Code of Health and Disability Services Consumers' Rights, other relevant legislation and approved guidelines.

1.8.2: The policies/procedures clearly guide service providers in obtaining informed consent from consumers/kiritaki.

1.8.3 Informed consent policies/procedures identify:

- (a) Recording requirements*
- (b) Information (including documentation) to be provided to the consumer/kiritaki by the service;*
- (c) Consent processes for the following situations, appropriate to the service and setting:*
 - (i) Routine situations*
 - (ii) Emergency situations*
 - (iii) Do not resuscitate situations*
 - (iv) Consumers/kiritaki who are unable to consent*
 - (v) Children and young people*
 - (vi) Involvement in teaching*
 - (vii) Involvement in research*
 - (viii) Storage, disposal and return of body parts/tissues etc.*
 - (ix) The use of advance directives*
 - (x) Meeting the needs of consumers/kiritaki with disabilities*
 - (xi) Other situations appropriate to the service where informed consent is required.*

1.8.4 Service providers receive ongoing training/education in the principles and practice of informed consent.

1.8.5 Service providers implement the specific requirements of informed consent as specified in the policies/procedures.

1.8.6 The effectiveness of the informed consent procedure is evaluated, recorded and reviewed (eg by consumer/kiritaki input, internal audit, peer review etc) at regular intervals.