

Informed Consent Guidelines



MINISTRY OF EDUCATION
Te Tāhuhu o te Mātauranga



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Section A:

Overview

Background

Informed consent legally applies to the provision of health and disability services. As well as ensuring that there is a process for obtaining initial informed consent it is also important to ensure that informed consent is an ongoing process throughout service delivery.

“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” (*Fraser, 1998, p.1*).

Informed consent is an integral aspect of service provision. It is also an ethical and legal requirement under the codes of ethics of various professional bodies, the Health and Disability Act (1994), and Code of Health and Disability Services Consumers’ Rights (1996).

These guidelines are about informed consent under the Code of Health and Disability Services Consumers’ Rights.

Legal context

Under the Code of Health and Disability Services Consumers’ Rights (the Code), no health or disability service can be provided without informed consent. Ministry of Education (the Ministry) staff working with children and young people with disabilities must comply with the requirements of the Code.

“The Code of Rights cannot be read in isolation from other legal rules,” (*Fraser, 1998, p.3*).

Service delivery within the Ministry often involves adherence to a number of legal requirements under various Acts, eg:

- The Privacy Act (1993)
- Care of Children Act (2004)
- Copyright Act (1994)
- The Official Information Act (1982)

It is important to remember that informed consent is primarily about ‘service provision’. The Acts listed above

focus on other matters, eg, the Privacy and Official Information Acts are concerned with access to information, handling and sharing of information.

(Please refer to the diagrams in Appendix 1 and the Frequently Asked Questions in Appendix 3 for examples of how these Acts interact with the process of informed consent.)

Informed consent is basic to the individual's freedom, rights and self-determination.

It comprises four key elements:

1 Competence

The person giving consent for a service either for themselves or for others (eg, their young child) must have the ability and/or support to make a decision based on the information provided. Competence is not determined by age but rather, the ability to make the decision.

2 Voluntarism

The consenting party must have been able to make the decision of their own free will. They also have the right to withdraw that decision at a later date.

3 Full information

All necessary information must be given to allow the consenting party to make an informed choice about service delivery options.

4 Full comprehension

Information needs to be given in an environment that enables open and honest communication. There must be opportunities to freely ask questions about any aspect of the service being offered. Interpreters should be used, where necessary.

In summary, this means that the person giving the informed consent for a service, either for themselves or for others (eg, their young child), must be competent to make the decision, participate voluntarily, have received full information and comprehended it, and understood the implications of agreeing to the service.

Ethical context

There are five occupational groups working in the Ministry who have published professional codes of ethics. These are early intervention teachers, occupational therapists, physiotherapists, speech-language therapists, and psychologists.

Examples of statements included in their codes of ethics are:

“Psychologists recognise that obtaining informed consent from those with whom they are working is a fundamental expression of respect for the dignity of persons and peoples”
(*Psychologists Code of Ethics, 2002, 7.1*).

This statement is supported by nine examples of practice implications.

Occupational therapists “will ensure consumers are able to make informed choices and give informed consent in writing, except where an enactment, the Code of Health and Disability Services Consumers’ Rights or common

law provides otherwise, before commencement of any intervention/ service, or consumer participation in studies or research...” (*Occupational Therapists Code of Ethics, 2002, 3.2*).

Early intervention teachers “will work to develop positive relationships with families and whānau that are based on shared decision-making, mutual trust and open communication... They will provide full and accurate information to families in language that is clear and understood to enable them to make informed decisions”
(*Early Intervention Teachers Code of Ethics, 2003*).

Section B:

Guidelines for obtaining informed consent

Who can give informed consent?

The Code of Health and Disability Services Consumers' Rights requires that informed consent is given by "the consumer".

There is no particular age at which children or young people may give informed consent under the Code. The focus is instead on the competence of the child or young person to comprehend what they are agreeing to.

These guidelines focus on parents or legal guardians providing informed consent as in many situations practitioners will be working with children and young people who may not be 'competent' to give informed consent.

Informed consent is about service delivery, not access to services. Access to services, often called 'referral', is a separate process (see *Appendix 2 for further clarification*).

What do practitioners need to do?

In conjunction with adherence to the four key elements of informed consent – competence, voluntarism, full information, and comprehension – there are key aspects about services that practitioners need to ensure they discuss with families/legal guardians at the initial meeting.

These are listed below and reflected in the initial informed consent discussion checklist.

Practitioners need to:

- 1** provide information and answer questions about services (Right 6 of the Code). This information will include the names and roles of practitioners who will be working with the child or young person,
- 2** provide information that addresses the concerns and/or presenting needs identified at the time of referral. Assessment processes and service options, and their advantages and disadvantages must also be explained (Right 6 of the Code),
- 3** inform parents/legal guardians that information about any changes in personnel or service delivery will be provided throughout the course of the service. These changes include information about any proposed assessment procedures or changes in service provision model. How information will be provided should also be discussed at this time,
- 4** discuss the right to withdraw consent for any aspect of the service at any time,
- 5** explain the process for accessing information held by the Ministry about their child, or young person,
- 6** provide information for parents/legal guardians about their rights and limits with respect to privacy (see the privacy statement at the bottom of the Initial Informed Consent Discussion Checklist). Also discuss the sharing of information with relevant others, eg, primarily educators, but sometimes health agencies, and welfare,
- 7** share information about the Ministry's complaints procedure.

Evidence of ongoing informed consent

Informed consent is an ongoing process. It is desirable to have the Initial Informed Consent Discussion Checklist signed by the parent or legal guardian but it is not necessary to have ongoing consent signed. However, practitioners must ensure that they have made file entries noting the detail and dates of all informed consent discussions, for example; any changes in practitioners, discussions regarding changes to programming or use of assessments, or agreement to have a tertiary student observe or work with the child or young person.

Cultural considerations

Practitioners must make every effort to ensure that informed consent discussions are culturally responsive by:

- allowing appropriate time for decision-making, requesting the assistance of cultural advisors, eg, kaitakawaenga,
- ensuring that children and families/whānau are fully informed in a manner they understand,
- taking into consideration the implications of providing a service for a child who has been ‘gifted’ to a family (as in a number of Māori and Pasifika families), but where no formal legal arrangement has taken place (*refer to ‘compliance with the code’ in the next section for more detail*),
- using interpreters for families whose first language is different to that of the practitioner, and
- acknowledging the importance of including the wider family/whānau in decision-making, and recognising the importance of community networks.

Guidelines for research that involves individuals

In the case of research that involves individuals (as opposed to aggregate data) separate consent must be agreed to in writing by each individuals parent/legal guardian. Research requests require ethics approval from an accredited ethics committee and written endorsement from a manager. The Ministry’s Ethics Advisory Team also provides advice to managers regarding research requests. Copies of any signed agreements should be with the child or young persons file.

Compliance with the Code

“The onus is on the provider to prove that it took reasonable actions to comply with the Code” (*Code of Health and Disability Services Consumers’ Rights, section 3*).

Where all efforts to contact a parent or legal guardian have

proved unsuccessful, it is still possible to provide services for the child or young person without obtaining informed consent.

For Ministry practitioners this would only apply in ‘exceptional’ circumstances and would involve

discussion with relevant managers. In such cases it would be necessary to contact a family or whānau representative and/or educators, or some other suitable person to ascertain their views (Right 7(4) of the Code). However, legally this would not be considered “informed consent”.

Privacy Act

There is often confusion about the role of the Privacy Act (1993) and Informed Consent.

The Privacy Act regulates the collection, storage, and subsequent use of personal information. When we handle personal information, we need to make sure that we comply with the Act. The focus of the Act is on good information handling practices, particularly on handling personal information consistently with the purpose for which it is collected. ‘Personal information’ means information about an identifiable individual.

The Act has 12 principles called Information Privacy Principles (IPPs) which apply to every agency that collects or holds personal information. The principles are summarised on the Ministry website as:

- Personal information is only to be collected by an agency

for the necessary, lawful purposes of the agency

- Personal information should be collected directly from an individual
- Where an agency collects personal information from an individual it needs to ensure the individual knows about the collection, its purpose, the use to which the information is to be put, and who the information is to be disclosed to
- Legal and fair means to be used in the collection of personal information Disclosure/Use/Retention
- Agencies have a duty to protect personal information against loss and unauthorised use or disclosure
- An individual is entitled to access personal information held about them

- An individual is entitled to request correction of information held about them
- Agencies are to ensure personal information is accurate before use
- Personal information is not to be kept longer than necessary
- Personal information collected for one purpose should not be used for other purposes unless the use falls within a listed exception
- Personal information is not to be disclosed to other agencies, bodies, or persons unless the disclosure falls within a listed exception
- Unique identifiers shall not be assigned to individuals unless it is necessary for an agency’s functions and the same unique identifier cannot be used by another agency

Relevant References

Statutory Provisions and Professional Body Requirements

The Health and Disability Commissioner Act (1994)
<http://www.legislation.govt.nz/act/public/1994/0088/latest/DLM333584.html>

The Code of Health and Disability Services Consumers' Rights (1996)
<http://www.hdc.org.nz/the-act--code/the-code-of-rights>

Codes of Ethics

New Zealand Early Intervention Teachers Code of Ethics (2003)
<http://www.earlyinterventionassociation.org.nz/>

New Zealand Occupational Therapy Board Code of Ethics (2000)
<http://www.otboard.org.nz/>

New Zealand Physiotherapists' Code of Ethics (2003)
<http://www.physiotherapy.org.nz/>

New Zealand Speech-Language Therapists Association Code of Ethics (2008)
<http://www.speechtherapy.org.nz/about-nzsta/ethics>

New Zealand Psychological Society Code of Ethics (2002)
http://www.psychology.org.nz/Code_of_Ethics

References

Practice issues relating to consent issues in New Zealand are discussed in these articles:

Consent in Child and Youth Health: Information for Practitioners, Ministry of Health (1998)

Frankfort-Nachimias, C. & Nachmias, D. (1996). *Research methods in the social sciences* (5th ed.). New York: St. Martin's Press.

Informed Choice – Not a Matter of Negotiation, Health & Disability Commission (2000)

The Code of the Protection of the Rights of the Vulnerable Consumers in Disability Services, Health and Disability Commission, conference paper (2001)

The Informed Consent Process and The Application of the Code to Children, Annie Fraser, Office of the Health & Disability Commissioner (1998)

Appendices

- This section contains:

- **Appendix 1:**

- Diagrams showing the relationship between informed consent and other requirements or Acts of Parliament

- **Appendix 2:**

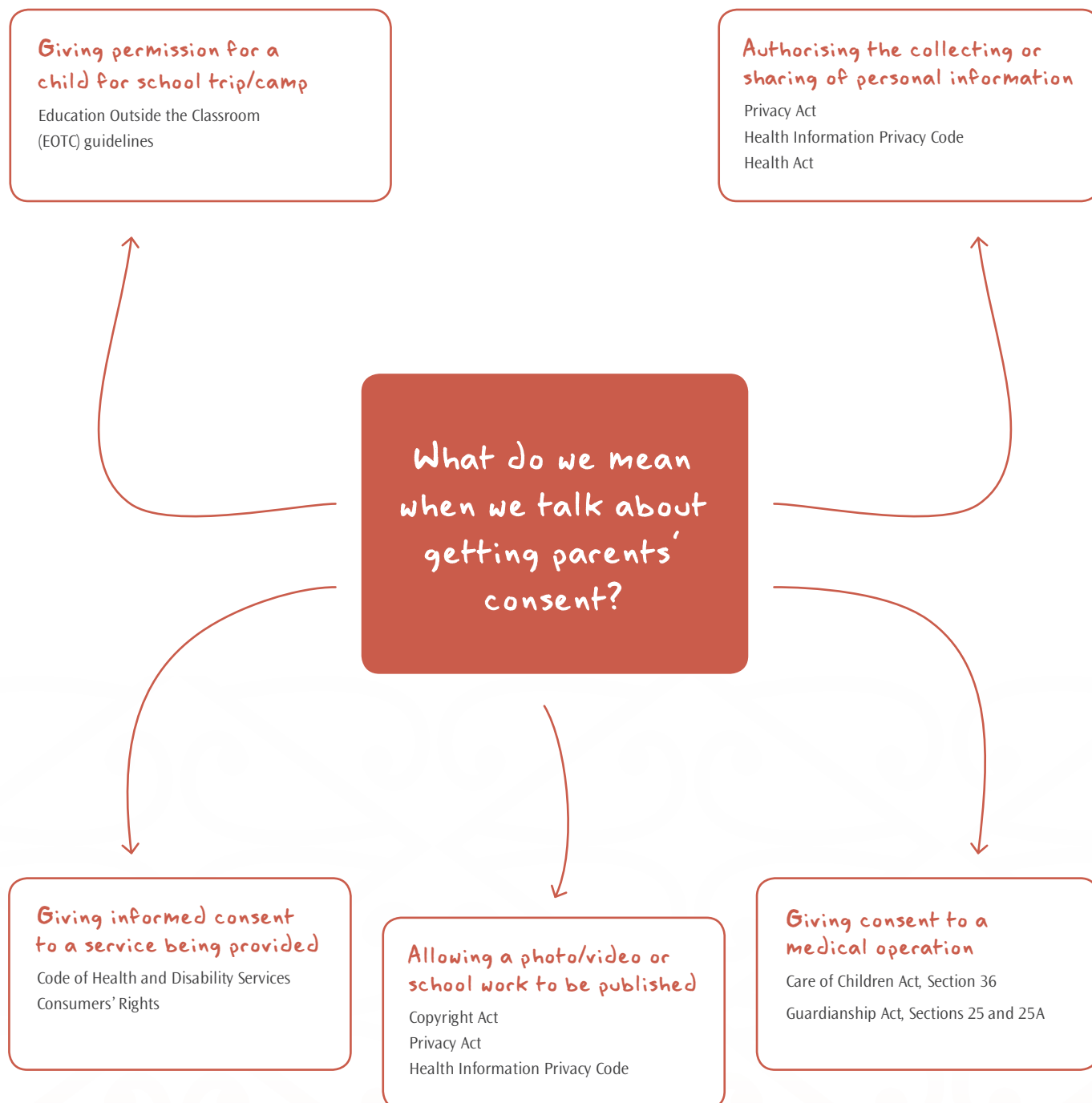
- A flow diagram showing the relationship between referral and informed consent

- **Appendix 3:**

- Frequently asked questions

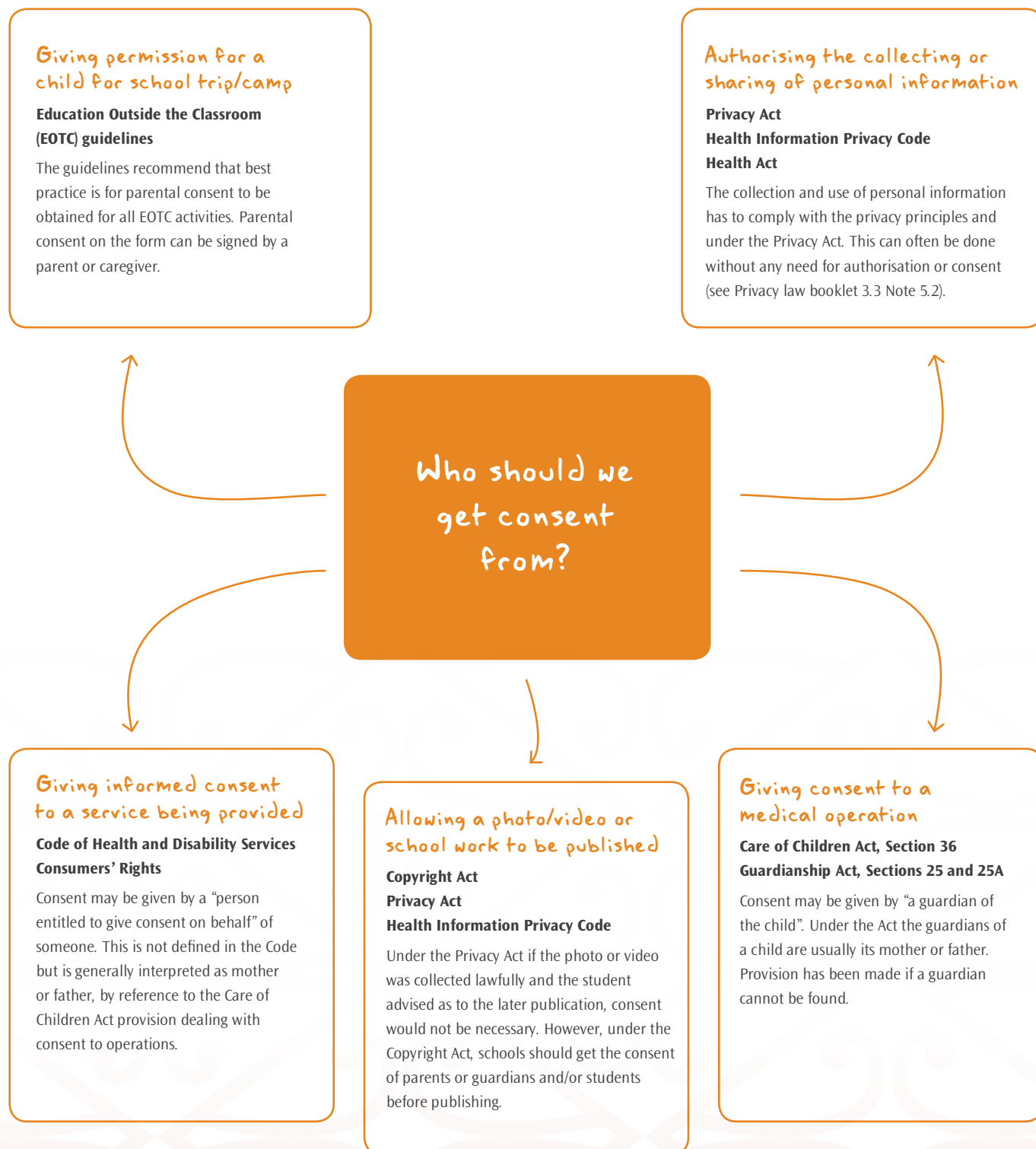
Appendix 1

Diagram 1: Parental consent



Appendix 1

Diagram 2: Consent for different purposes



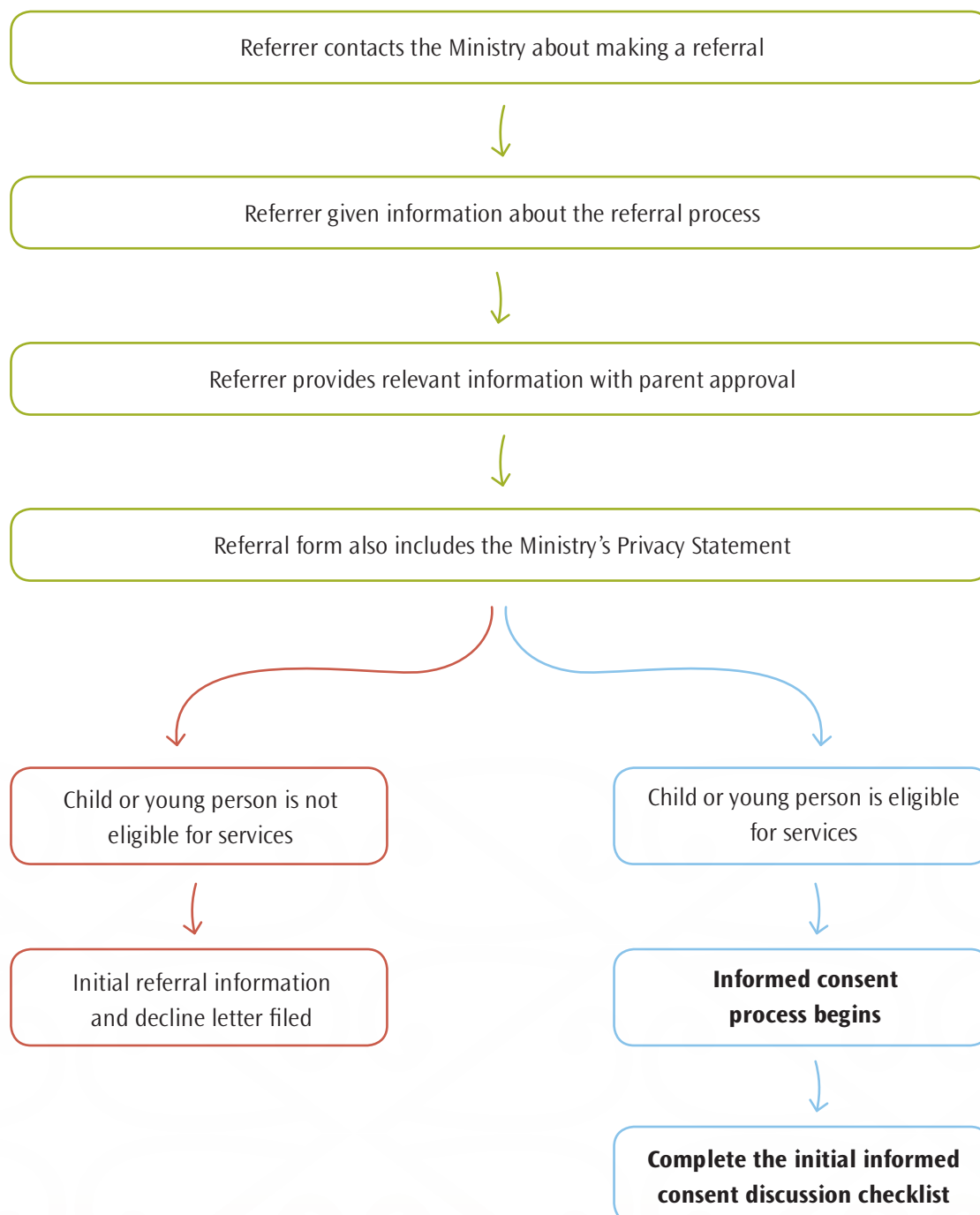
Appendix 1

Diagram 3: Further information



Appendix 2

Initial Referral Process and Link to Informed Consent



Appendix 3

Frequently asked questions

1. Why isn't the signature on the referral enough for informed consent?

The signature on the initial referral form is agreement only to making the referral. The discussion about how services will be provided is where informed consent to service delivery, and what that entails, takes place.

2. Does the Initial Informed Consent Discussion Checklist need to be signed?

It is desirable that it is signed as evidence that the initial discussion has taken place and the parent/legal guardian has understood the information. However, legally the parent does not need to sign the document. We ask that the practitioner sign it and place on the child or young person's file as evidence of the initial discussion.

3. What do I need to say about the privacy statement?

You need to ensure that the parents/legal guardians have been informed about the Ministry's privacy statement. This is written at the bottom of the Initial Informed Consent Discussion Checklist. This is the Ministry's position on how personal information is handled. The parent does not need to sign to say that they agree.

4. Do we need to have informed consent for a one off visit to a child and/or family/whānau?

One off visits are a form of service delivery. Children and young people and their respective parent/legal guardian have the right to be informed about any form of service delivery.

5. Why do I need consent for any changes to service?

Ongoing consent for any changes to service delivery is part of the legal requirement under the Code of Health and Disability Services Consumers' Rights (the Code). This can take many forms eg, face-to-face conversations, phone conversations, copies of letters, emails and reports. Refer to section B(3) of the guidelines for more detail.

6. What evidence does there need to be of ongoing informed consent?

There need to be file notes which are dated and explicit about the nature of any significant informed consent communications eg, referral to another agency, change of practitioners.

7. What happens if I am not able to make contact with the parents or legal guardian?

The Code allows for situations where all efforts to contact a parent or guardian have proved unsuccessful. Under 7(4) of the Code, if the provision of services is in the child's best interests, and you had tried but been unable to contact a parent or legal guardian, you can still provide a service. You must have taken into account the views of other suitable persons such as a family or whānau representative and/or the educators. This would only be in exceptional circumstances and carefully documented e.g. attempts to contact the parents and people consulted with, including managers.

8. Can I discuss the child or young person's issues with other agencies who might be involved?

The Initial Informed Consent Discussion Checklist contains a privacy statement about the sharing of information.
"Information may be shared with the child or young person's school or early childhood education provider, but is not shared with other agencies except where necessary for the provision of services, or as authorised or required by law".

It's best practice to clarify this with the parents/legal guardians during the initial informed consent discussion who information will be shared with. See the booklet *Privacy Law Guidelines* (pages 8, 9, 15 and 25). Contact Legal Services if you need further help.

9. Who does the information in Ministry files belong to?

The file belongs to the Crown under the Public Records Act, the information is a public record. If a parent asks for a file, this would be considered an information request under either the Privacy Act or the Official Information Act. See the Privacy Law guidelines for how to deal with a request (pages 10, 11 and 16). However, each Ministry office will have a local policy which reflects these guidelines. Parents are able to request copies of their child's file information and ask to have any inaccurate information corrected.

10. Is the Ministry allowed to keep the original file? What happens if the parent requests that it not be held by us or that it be destroyed?

The Ministry must keep the original file as it is a public record and subject to the Public

Records Act. A parent cannot require that a file be destroyed or the original handed over.

11. Who is allowed to access information on the children and young people's Ministry files?

The initial informed consent checklist contains a privacy statement about access to and the sharing of personal information.

"The Ministry of Education collects personal information about children and young people to support their learning and ensure that effective services are provided. Personal information is also used for quality assurance purposes to improve the quality of services provided, and for associated administrative and accountability purposes". People who can access the information are staff who are directly involved in providing services and other Ministry approved personnel eg auditors may also access the information for the purpose of monitoring and improving the quality of services.

This should be made clear to the parents/legal guardians in the initial informed consent discussion.

See the booklet *Privacy Law Guidelines*. Contact Legal Services if you need further help.

12. Who does the information collected belong to?

The privacy statement (which reflects the Privacy Act) is clear that the information collected belongs to the organisation (the Ministry) that collected it, not the individual practitioner. The Ministry has a duty to guard against loss of the information or unauthorised access or use. Maintenance of privacy and confidentiality and use of information for proper purposes are obligations for all Ministry staff under the Code of Conduct

13. What happens if the information I collect is highly sensitive and I am concerned about it being shared with others?

There may be instances where information is deemed to be highly sensitive and staff are concerned about sharing it with others. In these cases a discussion with your line manager is required. One approach would be to put a note on CMS stating that the information exists but the file is held securely off the system. The note should say where the information is held and how access might be obtained.

14. Ministerials: Can Members of Parliament (MPs) ask the Ministry for information about Ministry clients without authorisation from parents? Can MPs disclose personal information about Ministry clients to other people without authorisation from parents?

Disclosure of personal information to and by an MP is subject to the Privacy Act principles. The Ministry and MPs are able to disclose personal information without authorisation in certain circumstances. The Privacy Commissioner has published a checklist on this. Go to: www.privacy.org.nz/.

Consult Legal Services if you would like advice in this situation.

15. Do both parents have to consent if the main caregiver parent is adamant that contact with the other parent would be detrimental to the child's safety?

It is not a legal requirement for you to obtain the consent of both parents. Good practice would suggest that in this situation it would be advisable to work with both parents to achieve a solution in the interests of the child.

16. What about the Care of Children Act 2004 and the implications for us getting both parents' signatures?

The requirement relating to consent under this Act applies to medical procedures. The Act does not require the signatures of both parents.

17. What role does the school have in relation to informed consent, eg, can they give it under 'loco parentis'?

The loco parentis doctrine is generally considered no longer relevant in the school environment. Informed consent has to be given by a parent or legal guardian. Ministry staff could ask the school to assist in some situations.

18. If Child Youth and Family (CYF) is the legal guardian who do we get informed consent from – is it the social worker?

This will depend on whether the social worker has sufficient authority or the delegation, to sign off on behalf of CYF as guardian. You will need to check with the social worker in each instance.

19. If the child is in shared custody with Child Youth and Family and they agree to a service but the parents say 'no' whose word do we take?

If Child Youth and Family has guardianship, this is the same sort of problem as when parents disagree. You should try to gain agreement of both parties but if this was not possible and the service was considered to be in the child's best interest, then you could provide the service with the consent of one party only.

