



Informed Consent Guidelines

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SECTION A : OVERVIEW

Background

“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. GSE staff working with students 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 GSE 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 and information sharing.

(Please refer to the diagrams in Appendix 1 and the Frequently Asked Questions in Appendix 4 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:

▲ 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 a decision.

▲ 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.

▲ Full information

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

▲ 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 have understood the implications of receiving the service.

Ethical context

There are five occupational groups working in GSE 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 these 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 : PROCEDURAL GUIDELINES

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

In conjunction with adherence to the four key elements of informed consent – competence, voluntarism, full information, and comprehension – there are key requirements for GSE practitioners to follow to ensure that they are meeting legal and ethical requirements. These are listed below and a checklist is attached as Appendix 3. It may be useful to use this checklist to ensure that all relevant communications have taken place at the commencement of a service.

The practitioner must:

1. provide information and answer questions about GSE services (Right 6 of the Code). This information will include the names and roles of GSE 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. It also must explain the assessment process and service options, and their advantages and disadvantages (Right 6 of the Code),
3. provide information for parents or guardians and the child or young person, as appropriate, about their rights and limits with respect to confidentiality. Also discuss the sharing of information with relevant others, eg, teachers, health agencies, welfare, and in supervision,

4. explain the process for accessing information about their child held by GSE,
5. share information about the GSE complaints procedure (as it relates to service provision),
6. inform service recipients that ongoing information about any changes in GSE 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. These changes may also relate to any change in educational setting for the child or young person. How information is provided would need to be discussed at the time, and
7. discuss the right to withdraw consent for any aspect of the service at any time.

Who may 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 may give informed consent under the Code and the focus is instead on the competence and understanding of the child in any given situation.

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

Procedural 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, and information sheets for parents and the child or young person must be adapted for each new situation. Research requests require ethics approval from an accredited ethics committee and written endorsement from a GSE manager. Copies of any signed agreements should be with the file.

Evidence of ongoing informed consent

Informed consent is an ongoing process. It is not essential to have signed consent from the parent or child and young person at any point in the process unless it is a separate issue such as 'research'. However, practitioners must ensure that they have signed their file entries noting the detail of all informed consent communications, for example:

- ▲ agreements to share information with specified others, eg. teachers, health professionals,
- ▲ discussions regarding any changes in GSE practitioners,
- ▲ discussions regarding changes to programming or use of assessments, and
- ▲ agreement to have a student from a secondary school or tertiary provider observe or work with the child or young person.

Cultural guidelines

“The value of personhood has different meanings in different cultures. Within Anglo-European culture, individual independence is highly valued. Māori, Pasifika and some other cultures understand the value of personhood as something realised more completely through collectivity” (*Ministry of Health, 1998, p.2*).

Practitioners must make every effort to ensure that communication and the process is culturally appropriate by:

- ▲ acknowledging the importance of including the wider family in decision-making, and recognising the importance of community networks,
- ▲ allowing appropriate time for decision-making,
- ▲ requesting the assistance of cultural advisors, eg. kaitakawaenga, Pasifika liaison advisors,
- ▲ ensuring that children and families 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*), and
- ▲ using interpreters for families whose first language is different to that of the GSE practitioner.

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 guardian have proved unsuccessful, it is still possible to provide services to a child without obtaining informed consent. For GSE practitioners this would only apply in ‘exceptional’ circumstances and would involve discussion with relevant managers and supervisors. In such cases it would be necessary to contact a family or whānau representative or some other suitable person to ascertain their views (Right 7(4) of the Code).

However, legally this would not be considered “informed consent”.

Summary statement

The child or young person is the central focus of service provision. Informed consent is an integral part of effective practice and enhances outcomes for children and young people through quality engagement.

Acknowledgements

Thank you to the GSE staff who provided the working party with draft guidelines developed in the Northern and Central North regions. This provided the basis for these guidelines.

Thank you also to the wider Ministry of Education reference group who informed the process, with representatives from Māori, Pasifika, legal, operational policy, professional practice, service development and support, GSE practitioners, and a Special Education Facilitator.

Also thank you to stakeholder groups who have contributed to this work: representatives of parents, NZEI, the school sector, the early childhood sector, Resource Teachers: Learning and Behaviour, and the Health and Disability Commission.

Relevant references

STATUTORY PROVISIONS

The Health and Disability Commissioner Act (1994)

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

CODES OF ETHICS

- ▲ New Zealand Early Intervention Teachers Code of Ethics (2003)
- ▲ New Zealand Occupational Therapy Code of Ethics (2000)
- ▲ New Zealand Physiotherapists' Code of Ethics (2003)
- ▲ New Zealand Speech-Language Therapists Association Code of Ethics (2000)
- ▲ New Zealand Psychological Society Code of Ethics (2002)

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)

WEB PAGES

- ▲ Health and Disability Commission: www.hdc.org.nz/index.php
- ▲ Ministry of Health: www.moh.govt.nz

APPENDIX 1



Giving permission for a child for school trip/camp

Education Outside the Classroom (EOTC) guidelines

The guidelines recommend that best practice is for parental consent to be obtained for all EOTC activities. Parental consent on the form can be signed by a parent or caregiver.

Authorising the collecting or sharing of personal information

Privacy Act
Health Information Privacy Code
Health Act

The collection and use of personal information has to comply with the privacy principles and under the Privacy Act this can often be done without any need for authorisation or consent (see Privacy law booklet 3.3 Note 5.2).

Who should we get consent from?

Giving informed consent to a service being provided

Code of Health and Disability Services Consumers' Rights

Consent may be given by a "person entitled to give consent on behalf" of someone. This is not defined in the Code but is generally interpreted as mother or father, by reference to the Care of Children Act provision dealing with consent to operations.

Allowing a photo/video or school work to be published

Copyright Act
Privacy Act
Health Information Privacy Code

Under the Privacy Act if the photo or video was collected lawfully and the student advised as to the later publication, consent would not be necessary. However, under the Copyright Act, schools should get the consent of parents or guardians and/or students before publishing.

Giving consent to a medical operation

Care of Children Act, Section 36
Guardianship Act, Sections 25 and 25A

Consent may be given by "a guardian of the child". Under the Act the guardians of a child are usually its mother or father. Provision has been made if a guardian cannot be found.

Giving permission for a child for school trip/camp

Education Outside the Classroom (EOTC) guidelines
www.tki.org.nz/e/community/eotc

Authorising the collecting or sharing of personal information

Privacy Act
Health Information Privacy Code
Health Act
www.privacy.org.nz

Where can I find further information?

Giving informed consent to a service being provided

Code of Health and Disability Services Consumers' Rights
www.hdc.org.nz/index.php

Allowing a photo/video or school work to be published

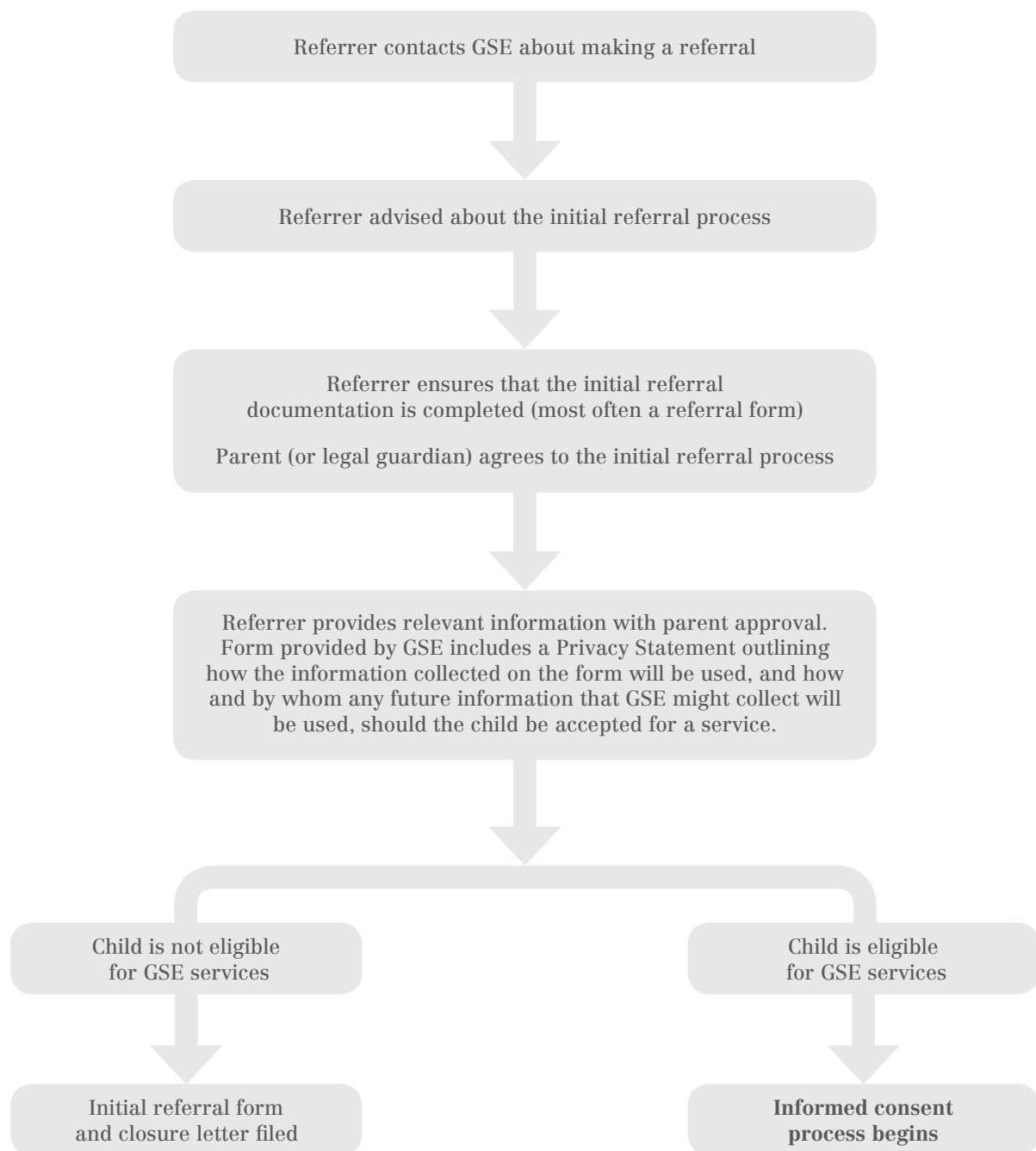
Copyright Act
Privacy Act
Health Information Privacy Code
www.tki.org.nz/r/governance/curriculum/copyguide_e.php

Giving consent to a medical operation

Care of Children Act, Section 36
Guardianship Act, Sections 25 and 25A
www.courts.govt.nz/family/

APPENDIX 2

Initial Referral Process and Link to Informed Consent



APPENDIX 3

Ministry of Education, Special Education (GSE)

Ministry of Education, Special Education (GSE) Initial Informed Consent Form

As a parent/guardian/child/young person I have had explained to me:

	Parent/Legal Guardian and Child/ Young Person (as appropriate)	Special Education Practitioner checklist
1 What GSE provides, and the names and roles of those who will be working with my child	<input type="checkbox"/>	<input type="checkbox"/>
2 Information about the issue that my child was referred for, the assessment processes, and service options available to me	<input type="checkbox"/>	<input type="checkbox"/>
3 My rights with regard to confidentiality including: <ul style="list-style-type: none">• What will happen to any records held by GSE• The process for sharing information with others e.g. teachers and health professionals	<input type="checkbox"/>	<input type="checkbox"/>
4 The process for accessing information held by GSE	<input type="checkbox"/>	<input type="checkbox"/>
5 GSE's complaint's procedure	<input type="checkbox"/>	<input type="checkbox"/>
6 How information about service provision or any changes will be communicated, including: <ul style="list-style-type: none">• Assessment processes• Services available• People who will be working with my child	<input type="checkbox"/>	<input type="checkbox"/>
7 The right to decline services offered by GSE, and the right to withdraw consent at any time	<input type="checkbox"/>	<input type="checkbox"/>

Parent/Guardian/Child (please print and sign)

GSE Practitioner (please print and sign)

Name:

Name:

Signed:

Signed:

Dated:

Dated:

Note:

It is preferable that initial consent is obtained in person. If this is not possible, initial consent may be obtained through telephone discussion, noted and signed on file by a staff member.

APPENDIX 3

Ongoing Informed Consent

(for significant changes to service, ref page 5)

Date:	Notes:

APPENDIX 4

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 around what happens next in terms of service delivery is where informed consent to service delivery and what that entails takes place.

2. Why do we need to have informed consent to 'screen' a child?

Screening is a form of service delivery. Children and their respective parent/legal guardian have the right to be informed about any form of service delivery, including screening.

3. Why do I need to keep getting consent for any changes?

It is critical that initial informed consent has taken place and continues to occur for every phase of service delivery. This can take many forms eg, face-to-face conversations, phone conversations, copies of letters, emails and reports. Refer to section B (6) of the guidelines for more detail.

4. How am I going to get time to do this?

We must work within our legal and ethical boundaries but informed consent is also about 'best practice'. Investing time in quality engagement enhances relationships, service delivery and outcomes.

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

The Code of Health and Disability Services Consumers' Rights provides that where all efforts to contact a parent or guardian have proved unsuccessful, it is still possible to provide the services to a child without obtaining informed consent.

Under 7(4) of the Code, if your provision of services was in the child's best interests, and you had tried but had been absolutely unable to contact a parent or guardian, and you had taken into account the views of other suitable persons such as a family or whānau representative and/or the teachers, then you could provide services to the child. This would only be in exceptional circumstances, in discussion with line managers, and carefully documented e.g. attempts to contact the parents and people consulted with.

6. Can an extended family member give informed consent if they are not the legal guardian? It is quite common in Māori and Pasifika families for children to be 'gifted' to another family member without formal legal processes having taken place.

The Code of Health and Disability Services Consumers' Rights refers to "people entitled to give consent on behalf of the consumer". The people entitled to give consent on behalf of the child are the parent or legal guardian only. See 5 above for exceptional circumstances.

7. Can I discuss the child's issues with other agencies who might be involved?

Yes, you can, as long as the parents agree to this in the initial informed consent discussion. You would need to discuss each new request to share information, with the parents. The initial referral form should contain a privacy statement about the sharing of information.

See the booklet *Privacy Law Guidelines for Group Special Education* (pages 8, 9, 15 and 25). Contact Legal Services if you need further help.

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

There needs to be file notes which are explicit about the nature of any major informed consent communications. An 'initial informed consent checklist' is included (see Appendix 3). The back page is for recording ongoing informed consent decisions e.g. referral to another agency, change of personnel. It must be signed by the GSE practitioner. It is preferable that it is signed by the child's parent or legal guardian. The checklist outlines the minimum requirements for informed consent discussions. For **research requests** you need both a form that has been approved by an accredited ethics committee, and a letter from GSE management endorsing any research.

9. Who does the information in GSE files belong to? For example, is it the child, young person and their family, the wider Ministry of Education, GSE, or all three?

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 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 and Appendix 4 on page 28). However, each GSE office will have a local policy which reflects these guidelines. Also, families are able to request copies of information kept on file and have comments recorded where they disagree with any written material.

In terms of how long the file must be retained, the Public Records Act stipulates that all records must be kept until the Chief Archivist has said that they can be destroyed. See the Privacy Law guidelines (page 7).

10. Is the Ministry of Education 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 of Education 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 handed over.

Parents do have the right to have their concerns noted on the file and the right to have copies of information on the file or to view the file.

11. Who is allowed to access information, including files, held by GSE? For example:

- ▲ wider Ministry of Education colleagues or contractors working for the Ministry of Education,
- ▲ universities contracted in to do quality reviews for example,
- ▲ people doing quality review work,
- ▲ internal supervisors,
- ▲ colleagues as part of peer review process, and
- ▲ verifiers.

Others can access the information for specific and identified Ministry purposes if it was made clear to the parents in the initial referral process that you would be doing this. The initial referral form should contain a privacy statement about the sharing of information. See the booklet *Privacy Law Guidelines for Group Special Education*. Contact Legal Services if you need further help.

12. Ministerials: Can Members of Parliament (MPs) ask the Ministry for information about GSE clients without authorisation from parents? Can MPs disclose personal information about GSE 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 (See www.privacy.org.nz – Complying with the Act – Checklist for Ministers). Consult Legal Services if you would like advice in this situation.

13. 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.

14. 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.

15. What information should we give parents about schooling options?

Information about the range of different schooling options should be given for parental consideration. Enough objective information should be provided to allow the parents to assess the benefits and disadvantages of the various options.

16. 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 guardian. But GSE staff could ask the school to assist in some situations.

17. If Child Youth and Family 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 Child Youth and Family as guardian.

18. If the child is in shared custody with Child Youth and Family and it agrees 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.

19. If GSE practitioners are going to have tertiary students working with GSE children, must we get informed consent or should that be covered off in the initial referral?

You would need specific consent to have tertiary students working alongside practitioners. This could be specifically mentioned in the initial referral or you could gain consent at the time.

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