

Guidelines on Informed Consent

FEBRUARY 2017¹

Contents

The purpose of these guidelines	3
Ethical concerns	3
Legally binding	3
The Process	4
Informing the client	4
Fit for purpose	4
What the information should contain	4
Discussing alternatives	5
Being realistic about outcomes	5
The risks of proceeding/ not proceeding	5
Individual versus collective consent processes	5
Advance warning about constraints to confidentiality	5
Contractual details	5
Constraints	6
Comprehension	6
Power issues	6
Working with offenders	6
Court ordered assessment of an adult	7
Working with Māori	7
Children and young persons	8
Relevant legal frameworks	8
Consent in the context of Family Court disputes	9
Court ordered assessments of a young person	9
Defining a mature minor	10
Seeking consent from others	10
Can a child refuse treatment?	10
Separated parents	10
Informed consent with those who have reduced capacity to consent	11
Legal obligations	11
Defining competence	12
Those who are impaired	12

 $^{^{\}rm 1}$ First adopted by the Board in February 2016. Revised February 2017.

Cognitive decline in the elderly	12
Intellectual disability	13
Consent from an authorised other person	13
Where consent cannot be obtained due to incapacity or lack of proxy	13
Compulsory assessment and treatment under the Mental Health Act	13
Other court-ordered processes	13
Recording	13
Recording consent	13
Confidentiality constraints	14
Release of information	14
Reviewing consent decisions	14
The freedom to decline or withdraw consent	14
Revision of the informed consent	14
Establishing a culture of openness	14
Objectives may change	14
Research participation	14
Consenting to research participation	14
Children in research study	15
Practising on the internet	15
References	1.6

The purpose of these guidelines

The Health Practitioners Competence Assurance Act (the **HPCA Act**) mandates the New Zealand Psychologists Board (the **Board**) to assure the public of New Zealand that psychologists are fit to practise and that they provide high quality and safe services. In order to meet these obligations the Board has adopted the Code of Ethics for Psychologists Working in Aotearoa/New Zealand 2002 (the **Code**), (developed in conjunction with the New Zealand Psychological Society and the New Zealand College of Clinical Psychologists) as a guide to ethical practice. The Code delineates the manner in which psychologists ought to carry out their practice. All other statements of how psychologists should conduct their practice must be consistent with the Code and its ethical principles of respect for the dignity of persons, responsible caring, integrity in relationships, and responsibility to society.

Guidelines adopted by the Board support psychologists in providing competent and ethical practice by translating or expanding on the Code in relation to more specific aspects of their professional behaviour. Guidelines are not definitive, binding, or enforceable by themselves. They have the least authority of any of the regulatory documents. However, a disciplinary or review body may use the guidelines in evaluating a psychologist's knowledge and competency. Guidelines are recommendations rather than mandatory standards, but supplement the Code of Ethics which is the highest and most aspirational regulatory document. Consideration and the application of such guidelines are considered an essential component of continued professional development and of delivering "best practice".

Ethical concerns

In accordance with the Code of Ethics, a psychologist's professional relations with others promote beneficence or wellbeing, are based on respect for the other's autonomy, should not cause harm, and should be guided by principles of justice and fairness. These principles apply to all professional services and research endeavours. It is fundamental to the respectful relationship with the client (whether individual, group, or organisation) that the client is informed and participates as fully as he or she is capable of in consenting to research participation and/or determining the purpose of engagement with the psychologist.

The central purpose of the "Informed Consent" best practice guidelines is to promote practice consistent with these ethical principles.

Gaining informed consent means that the client has the right to choose whether to receive the psychological service (or to take part in research) based on the best information available, and to withdraw that consent should their opinion change. Informed consent should occur at the beginning of an engagement, should be documented so that there is a written record retained, and is often a dynamic process as the unfolding process requires revision of mutual understanding and agreement. Any changes to consent or withdrawal of what has been previously agreed should also be recorded in writing. These guidelines summarise key themes and principles about gaining informed consent.² The generic term "client" is used throughout to refer to any recipient of service, whether individual, couple, whānau, family, group, or organisation.

Legally binding

Although the Code of Ethics provides guidance to the profession and a code which an individual's professional behaviour can be compared against, it remains an aspirational document in legal terms. Psychologists are, however, legally bound to uphold the Health and Disability Commissioner's (**HDC**) Code of Health and Disability Services Consumer's Rights, in which Right 6 expresses a consumer's right to be fully informed and Right 7 expresses a consumer's right to make an informed choice and to give informed consent. The High Court

 $^{^2}$ See the relevant chapters on this topic within the NZ Psychological Society publication, "Professional practice of psychology in Aotearoa New Zealand" second edition (in press 2016) for a fuller discussion of the complex issues involved.

has upheld that effective informed consent is a fundamental right on the part of consumers of health services, and that whether or not the information is adequate is to be assessed from the viewpoint of the client. The Court considered that the provision of inadequate information, when the client needed that information for their decisions affecting treatment, will amount to professional misconduct.³

The Process

Although the process and principles of informed consent can be stated quite simply, translating them into action requires attention and sensitivity to a number of factors which can potentially compromise the client's ability to consent in an informed manner.

Consent to participate means that a client with decision-making capacity freely authorises a plan aimed at a mutually agreed goal. The consent or authorisation is informed when the psychologist discloses to the client sufficient relevant information to enable the client to make an informed decision about the relevant options for treatment (including no treatment) and any risks and benefits. This informed consent process is then documented thoroughly, including in the client records, consent forms, and client education materials. Any changes or later withdrawal of consent should also be fully documented.

A third party contracting a psychological service may have obtained consent from the client who is the intended recipient of the service. However the psychologist is advised to undertake his or her own informed consent process rather than relying on what may have been a generic consent process.

Gaining consent may be part of a process of ongoing evaluation and re-visiting of decisions. Respecting the client's autonomy is met by an honest effort to:

- Check the client has the capacity to make decisions.
- Disclose enough information for the client to make an informed decision.
- Ensure that the client demonstrates an adequate understanding of the disclosed information.
- Confirm that the client is freely authorising the plan.

It is likely that this assessment of capacity to understand consequences of possible choices and the discussion of informed consent are dynamic and will need to be revisited throughout the period of engagement, as both the evaluation of capacity and the choices made may evolve as the engagement deepens. The capacity to understand may also fluctuate, and the complexity of the decision-making may change.

Informing the client

Fit for purpose

The client should be informed of the intended aims and objectives of the engagement, using language, form of information, and manner that promotes understanding. Information may need to be adjusted to allow for any language or cultural barriers, as well as any cognitive or communication difficulties. The psychologist needs to ensure the client is as aware as possible regarding the purpose and process of the engagement. This may mean adapting and presenting information in a more accessible manner, for example using simpler wording. The client should be given time to consider the information given. The psychologist also needs to assess the client's understanding by asking the client to relate back their perception of the situation in their own words.

What the information should contain

Adequate information is what a reasonable consumer in that person's circumstances would expect to receive, including an explanation of their condition, what actions may be considered, and any recommendations for how to proceed. Information may also include the nature of the suggested psychological activity, the intended purpose, the likely benefits and

 $^{^3}$ Advice from Paul Radich QC (legal advisor to the Board) referring to the judgement of Elias J (as she was then) in B v Medical Council of NZ (2005).

any potential risks, any constraints on the confidentiality of the records arising, any alternative options, the time span for which permission to proceed has been given, and how consent may be reviewed or rescinded at any time. The understanding of what information is deemed to be relevant is likely to evolve as the engagement with a client unfolds.

The initial written information may also include the limitations of the service offered. For example, a private practitioner may choose to state that this service is not intended to be a crisis or emergency service, and to provide details of how to access the emergency service.

Discussing alternatives

Discussing options may include acknowledging alternative experts in the field (if available), less expensive options, public versus private services, and how to access these alternatives. Engagement for a contracted service (e.g., assessment for a third party) may involve discussion of the consequences of not complying.

Being realistic about outcomes

The nature of the psychological activity and the likely outcome of the service should be described, without overstating any anticipated benefits. By offering the service the psychologist is implicitly claiming expertise in that field, but care should be taken to not overstate their competence or the range of their experience. As noted above, it may be relevant to identify any alternative intervention approaches and how these other services could be accessed. The HDC Code of Rights states that, if asked, a psychologist is obliged to inform the client of their professional status and qualifications, their recommendation for any proposed action, how to obtain a second opinion, and the outcomes of relevant research.

The risks of proceeding/ not proceeding

It may be appropriate to inform the client of the consequences of not consenting to proceed. Any potential risks arising from psychological services or research participation should be discussed so that the client is forewarned as much as possible. This would include any fees payable, time estimates, and any privacy and confidentiality issues. It may be appropriate to inform the client that the treatment being proposed is still being developed and therefore there is not yet a strong evidence base. Any departure from established methods should also be carefully discussed and consent for any alternate approach sought.⁴

Individual versus collective consent processes

A focus on individuality is not necessarily appropriate within some collectives. Māori and Pasifika families place more emphasis on shared responsibility and permission giving, as do many in the Asian and Arabic communities. When a Māori person is seen, it may be more appropriate to offer the option of providing information to the whānau and allow time for the consent process to be gained from the wider group. This is likely to be a preferred way of proceeding, particularly when a child is the focus of concern. When the "client" is a couple or a group, all parties should confirm consent – optimally in writing.

Advance warning about constraints to confidentiality

Depending on the nature of the service, there may be circumstances where the psychologist chooses to forewarn the client that in the event of disclosure of illegal activity, or activity that places another person at risk, or reason to be concerned that the client may be at risk to him or herself, then the psychologist may feel ethically and morally bound to inform relevant other authorities.

Contractual details

It is expected that the written informed consent statement would include the reciprocal contractual details of the engagement, such as the expectations around payment for services, what notice of non-attendance applies, whether or not contact between sessions is applicable, the service offered for the fee, and any constraints to confidentiality (including the circumstances which may lead to disclosure and the name of the supervisor).

⁴ The inclusion of some alternative or natural healing approaches and faith-based approaches are considered departures from evidence-based psychological interventions and have been the basis of complaints received by the Board. While some natural healing approaches may have an evidence base, it should be declared as part of the informed consent process as outside the mainstream of what consulting a psychologist involves. Version: February 2017

Constraints

Comprehension

Client comprehension can be easily over-estimated. For example, an individual who is cognitively functional in normal circumstances may not absorb information in an unfamiliar context due to anxiety or preoccupation. Ability to understand can be impacted by a range of factors including (but not limited to) education, intelligence, cultural unfamiliarity, and age. A sensory disability such as deafness or blindness also may be a barrier to comprehension. English as a second language is also a possible constraint on understanding. The use of a translator may be advisable with some referrals, both with regard to gaining consent to proceed and possibly throughout the service provision.

Even when information is understood, clients may not use it to make an autonomous decision, instead preferring to delegate, defer to, or to make decisions in collaboration with their support network.

The time involved in undertaking a rigorous informed consent process may mean that it is sometimes short-circuited. Unless the client is empowered to question or ask for further explanation, they may feel rushed or pressured to consent.

Research to measure how much information is absorbed by patients in a health context found a wide discrepancy between what the health worker believed had been provided and how much was retained by the patient.⁵

Power issues

There are many issues which may compromise a client's ability to freely make their own choice. Compromise may occur because of the power imbalance implicit in the situation, a client's desire to please, or because of the situation. A compulsory treatment order may be in place, such as when a client is held as an inpatient under the Mental Health Act. In some situations compliance with treatment may be required before some desired consequence is gained, such as release from imprisonment.

A client may be highly motivated to receive help and therefore susceptible to being persuaded by the support offered by the psychologist. This initial engagement may confuse the process of sifting out the optimal service to address the client's most pressing needs. The psychologist may also be susceptible to overstating the expected positive outcome in their desire to help the client.

It behaves the psychologist to be sensitive to these issues and to the vulnerabilities of any parties to the engagement, to strive to promote the wellbeing of clients, and to minimise harm. Consent should not be based on suggestion or persuasion but on comprehension. The dignity of the client and their right to refuse engagement must be respected, even in situations where the psychologist does not agree with their choice. The record should document the options given and the choices made, with relevant related information. Consent may need to be sought to share this choice with others on whom it impacts (for example, others within a multi-disciplinary team, or reporting back to a third-party contracting organisation).

The contracted client may not be the person on whom the engagement impacts. This would apply, for example, where the psychologist is preparing a report for a third party or in organisational settings. Ethical practice may require breaking down the process of gaining informed consent into separate channels, depending on the perspectives of those involved.

Working with offenders⁶

An offender may be court-ordered to be assessed or to receive treatment. Consideration of "who is the client?" is likely to determine the psychologist's obligations with regard to sharing information gathered and the limitations to confidentiality. Gaining informed consent from the offender will require careful clarification of the consequences of participating versus not participating. The offender should have the mental capacity to understand the process and

⁵ Ancel, G. (2012).

⁶ Wilson, N., Tamatea, A., and Riley, D. (2007).

enter the assessment or treatment on a voluntary basis. The assessing psychologist should make a full disclosure on the reason for the procedure, to whom the information will be given, how the assessment will be undertaken (e.g., sources used for collateral information, psychometrics to be administered), the risks and benefits arising, and the alternatives to consenting. The mental capacity to understand the implications of assessment or treatment is indicated by the person being able to consider the risks and benefits in order to come to a reasoned judgement.

A psychologist may need to proceed with a court-ordered assessment without the consent of the individual concerned, drawing on file data and collateral sources. The conclusions and judgements drawn would be stated along with the limitations arising from subject's refusal to participate. The record documenting the process used to attempt to gain informed consent could be taken into account should there be a subsequent complaint.

Court ordered assessment of an adult⁷

There are a number of statutes which enable the Courts to order that a person undergo a psychological examination where their mental condition is relevant to any matter in question in a proceeding. Appellate courts have upheld the exercise by lower courts of their power where sufficient information was available to a lower court to warrant a report being ordered.

The principles of informing and gaining informed consent still apply in this mandated assessment scenario. The psychologist should give adequate information about the nature and scope of the assessment, the ways in which the report is likely to be used, and to whom the report will be made available. Information should also include the likely consequences of not cooperating with the report preparation.

If the consent to proceed is not freely given, the psychologist should record that and any constraints on the information available but proceed to the best of their ability in the circumstances.

Working with Māori

The principles of partnership, participation, and protection according to the Te Tiriti o Waitangi are applicable to all aspects of professional practice, including the process of informed consent. The principles in this context have been interpreted⁸ as:

"Partnership involves a collaborative formal relationship between psychologist and whānau, where the whānau feels empowered.

Participation is a culturally safe process of discussions and exchanging ideas.

Protection enables access to services where the duty to provide safety is the responsibility of the psychologist."

Respect for the diversity of persons is fundamental to the Code of Ethics. The Code recognises that Te Tiriti sets out the basis of respectful relations between Māori and Non-Māori. Although there is also wide variation among Māori, gaining informed consent in a manner that empowers involvement is an important start on establishing a professional engagement that enhances well-being and delivers the required service.

The Māori connecting principle, the whakawhanaungatanga, addresses the question "who are you?" which needs to be developed before the purpose of engagement is discussed. The establishing of relationship allows the individual, couple or whānau to make an informed decision whether or not this person is appropriate for them. This may involve sharing mihi, whakapapa, karakia and waiata to create a safe place "of joining in aroha" Once the

⁷ Advice of Paul Radich QC, Legal Advisor to the Board.

⁸ Cargo, T., Waitoki, W., and Feather, J. (2016)

⁹ Gilgen, M. (2016)

¹⁰ Cooper, E. and Rickard, S. (2016)

relationship is established, then the tasks of engagement can be discussed, to achieve informed consent.

The domain of the psychologist was referred to by one author as an "unfamiliar kaupapa" Many clients may be apprehensive or fearful prior to an assessment or engagement by a psychologist. The cultural divide may be even greater for Māori. Providing information in advance may help a Māori person or whānau to feel more comfortable and to know what to expect. A culturally appropriate greeting in Te Reo and where possible, offering a drink or refreshments may help create a sense of cultural safety.

Children and young persons

There is no particular age at which a child can consent to health and disability services. The law in this area:

"...demonstrates a clear trend away from age-related thresholds and, instead, focuses on the competence of the individual child. The relevant question does not focus on the age at which a child may consent validly to services. Rather, it focuses on whether the level of understanding of a particular child enables him or her to consent to a particular service. Minors may authorise medical treatment if they are mature enough to understand what is proposed and are capable of expressing their own wishes." 12

If a service is to be provided to a child, then consent may be obtained from the child's parent or guardian. However if the child is regarded as a mature minor, then that child is considered to have the capacity to consent (or to decline treatment) on his or her own behalf.

Relevant legal frameworks

The overriding principle is that the best interests of the child should be upheld. The Care of Children Act 2004 (**COCA**) makes the "best interests and welfare of the child" paramount in any legal dealings. This Act has superseded the Guardianship Act 1968 (refer section 25(1)) which provides that anyone over the age of 16 can give consent with the same effect as if that person was of full age.

Ordinarily both parents are considered the legal guardians of a child and consent from both parents should be sought in decisions that affect an infant or a child, including the decision to treat or assess. However if one parent refuses, under section 46R of the COCA a parent can apply to the Court to make the case for why the best interests of the child should override this opposition. In addition, a child who is deemed competent to decide may make his or her own decision to either consent or to withdraw consent for a course of action or treatment. Processes of seeking consent and any decisions arising should be fully documented in the client records, including options explored and who was consulted.

The United Nations Convention on the Rights of the Child (ratified by New Zealand in 1993) recognises the rights of the child to be seen as having individuality and therefore some autonomy, in addition to the right to be protected. This includes involving children in decisions about their health and welfare.

The Code of Health and Disability Services Consumer's Rights does not make a distinction between children and adults and all are presumed to be competent to make an informed choice, unless there are reasonable grounds for believing otherwise. Adults over the age of 18 are ordinarily assumed capable of giving informed consent. Children and young persons below this age may also be capable of doing so. Under the age of 16, a psychologist may see a young person without parental authority or knowledge if that young person is considered to have sufficient understanding to make their own informed decision.

¹¹ Dudley, M. (2016)

 $^{^{12}}$ Advice of Paul Radich QC, Legal Advisor to the Board. Version: February 2017

The Code of Ethics (refer clause 1.1.3) requires psychologists to seek the full and active participation of all persons in decisions that affect them. If there are limitations in competence to consent for themselves, the psychologist is nonetheless directed to seek informed consent to the extent that is feasible from that person (refer clause 1.7.3).

The changes introduced by the Vulnerable Children's Act 2014 will allow for some wider information sharing between education, health, and justice agencies in order to improve the protection and care of vulnerable children. If a child is identified as at risk, the parents or whānau would be asked for permission to share specified information to an information hub, in accordance with an Approved Information Sharing Agreement (allowed by the Privacy Amendment Act 2013). The family can ask for an agency to not receive their information and can also withdraw consent if they change their mind about sharing the information. Such hubs were in the early stages of development at the time these guidelines were being written,

In the event that the family or whānau does not give consent but there is deemed to be a significant risk to a child, then this matter should be reported to Child, Young Person, and Family Service or the Police, in accordance with the Privacy Act principle 11(f)(ii) and the Child, Young Person and Family Act 1989 (section 15).

Consent in the context of Family Court disputes

A psychologist who is contracted to assess, counsel, or to provide other psychological interventions to a child who is the subject of a Family Court dispute should take care to gain consent in writing from both parties before proceeding.¹³ This would apply whether the contract was from the Court or by private appointment. Taking care to inform and gain consent is respectful of the rights of both parents and also avoids the psychologist being drawn into one side of a parental conflict (which is unhelpful for the interests and welfare of the child). Section 16 of the COCA makes it clear that both parents (guardians) have the right to be involved in important matters affecting the child. While s 36(3) allows one guardian to give consent, in a Family Court dispute there is already an acknowledged disagreement between the parties over the child's care arrangements. The psychologist has a professional obligation to avoid bias or giving the perception of bias, and therefore should collaborate with both parents to achieve the best possible informed consent. The consent of both parents is more likely to protect the child's best interests by enabling a better assessment and may promote psychological safety for the child through the awareness of the involvement of both parents. In the event that consent is not forthcoming, the matter should be referred back to the Judge for direction.

Court ordered assessments of a young person

Assessments ordered by the Court provide circumstances that allow psychologists to proceed without informed consent. Sections 178 and 333 of the Children, Young Persons and their Families Act 1989 enable the Youth Court to order the provision of a psychological report on a child or young person to whom proceedings relate. The Court will order the child or young person to attend for a psychological examination and that the report be made available to the Court.

Although this provides a circumstance in which the psychologist may proceed without informed consent, the principles of providing information and seeking consent still apply. The psychologist is obliged to provide adequate information about the nature and scope of the assessment, about the use to which the resulting report will be put, and about the people who may have access to the report. The psychologist should then endeavour to obtain informed consent.

If a young person refuses to undergo an assessment, the Court may (if there is sufficient justification requiring the assessment) insist on it regardless. In the face of a refusal or minimal cooperation by a young person held in a Youth Forensic Service to participate in an assessment, the psychologist should use their best endeavours to provide adequate information, including the possible consequences arising by not providing information, to encourage (but not coerce) consent. It is desirable that the assessment is undertaken

Version: February 2017

-

 $^{^{13}}$ In June 2016 the Health Practitioners Disciplinary Tribunal issued a finding against a psychologist who failed to do this

collaboratively in order to report to the Court as fully as circumstances allow. In the absence of consent from the young person concerned, the psychologist may need to report back to the Court within the constraints that this imposes.

Defining a mature minor

The House of Lords Gillick v West Norfolk and Wisbech Area Health Authority (1985) decision ruled that a child's right to make their own decisions superseded parental rights of decision making when "a boy or girl is capable of understanding what is proposed and is capable of expressing his or her own wishes". The Court in the Gillick decision also stated that practitioners should make every effort to encourage the child to involve the parents.

The Supreme Court of Canada¹⁴ has addressed the issue of the identification of a mature minor and has defined the following checklist as an aid to assessing that the child's wishes reflect true, stable, and independent choices:

- What are the nature, purpose, and utility of the recommended treatment? What are the risks and benefits?
- Does the young person demonstrate the intellectual capacity to understand the relevant information and the potential consequences?
- Is there reason to believe the young person's views are stable and a true reflection of his or her core values?
- What is the potential impact of the young person's lifestyle, family relationships, and broader social affiliations on his or her ability to exercise independent judgement?
- Are there any existing emotional or psychiatric vulnerabilities?
- Does the young person's illness or condition have an impact on his or her decisionmaking ability?
- Is there any relevant information from adults who know the young person, such as teachers or doctors?

If a child is deemed mature enough to choose for him or herself, the role of the parent or guardian ideally becomes one of advisor and supporter.

Seeking consent from others

If the individual young person is not deemed capable of choosing for themselves, consent should be sought from both parents or a guardian who has the legal authority to choose on their behalf. The COCA allows for a person other than a parent to be recognised as a guardian by application through the Family Court.

Parental consent to initiating treatment does not necessarily mean that person receives full information about treatment progress or outcome. The child or adolescent may have variable competence with regard to consenting to treatment as compared with judging what information should be released and have an interest in keeping some information confidential.

A parent or guardian is able to consent to the child participating in a research study if that child has been given information and assented to involvement.

Can a child refuse treatment?

Competence to give informed consent also entails the right to decline treatment, should that be the considered opinion of the child. Literature cited by Rucklidge and Williams (2007) observed that there are rare occasions where the court has been used to overturn a child's decision on the grounds that it is in their best interests to receive that treatment. It seems that the test for competency when treatment is refused is more stringent than that used to assess competency to consent to treatment. Psychological treatments are unlikely to be of life preserving importance (although this may apply to severely eating-disordered clients) but a psychologist may be required to give evidence in such a case.

Separated parents

If the parents of a child are separated or divorced, there may be a court order in place which specifies who has the right to make decisions affecting the child's health. A psychologist

¹⁴ Decision A.C. v Manitoba, 2009 cited by College of Alberta Psychologists Professional guidelines for Psychologists (adopted 2001, revised 2010) "Limits to confidentiality and consent for services: Special issues in working with minors". Version: February 2017

should make "reasonable enquiries" to ascertain whether the parent seeking treatment for their child has the right to consent to treatment. It may be desirable to seek a copy of the court order establishing guardianship and the terms of this order. Unless the Family Court orders indicate otherwise, ordinarily both parents need to be consulted.

In a recent case in the United Kingdom (reported in a legal newsletter¹⁵), one parent wanted their child to be vaccinated but the other did not. The Court ruled that it was in the child's interest to be vaccinated and so overruled the objection. This problem becomes more complicated when children are old enough to have strong views about this issue themselves that conflict with the views of one or more of their parents. New Zealand law presumes anyone, regardless of age, is capable of providing informed consent to treatment, including vaccines, unless there are reasonable grounds to suggest otherwise. Children's views should always be taken into account by a court deciding such issues, although what a child wants may differ from what some other persons may deem to be best for the child's interests and welfare. Should a decision concerning a child or young person be disputed, the psychologist should fully document the process of seeking informed consent and record the reasons for the course of action (or inaction) chosen.

A Court can also overturn parental refusal or consent if it is deemed not in the child's interests.

Informed consent with those who have reduced capacity to consent

Legal obligations

The United Nations Convention on the Rights of Persons with Disabilities of obliges all spheres of life, both public and private, to be consistent with its principles of the full realisation of all human rights and fundamental freedoms for disabled persons. Article 12 of the Convention refers to equal legal rights, including respecting the rights, will, and preferences of the person without undue influence. The Convention affirms the individual's right to make their own decisions and to the need to respect their dignity and freedom of choice. This places the obligation on those in the roles of delivering services to lift the level of support to enable and empower those with reduced capacity to exercise their legal rights.

The Code of Ethics requires psychologists to seek to obtain as full and active participation as possible from all persons. The HDC's Code of Rights requires health practitioners to presume all recipients of health services are competent unless there are reasonable grounds for believing that the person is not competent. These codes are consistent with the Convention.

The Victorian Government disability services have produced a particularly useful supported decision-making framework¹⁷ which is based on the decision making principles:

- 1. Everyone has the right to make decisions about the things that affect them.
- 2. The capacity to make decisions must be assumed.
- 3. Every effort should be made to support people to make their own decisions.
- 4. Capacity to decide is decision-specific.
- 5. People have the right to learn from experience.
- 6. People have the right to change their mind.
- 7. People have the right to make decisions that others might not agree with.

A person may need additional assistance to understand and communicate their choice. It may be helpful to use different formats, communication aids, translators, or longer time frames to make decisions. Decision making capacity means understanding the situation and the decision required. It means understanding what the choices are, weighing up the consequences of the choices, how different choices may affect them, and then communicating their decision.

¹⁵ See Kensington Swan newsletter, 31 October 2013, at www.kensingtonswan.com/Legal-updates.

¹⁶ Signed by New Zealand in March 2007 and ratified September 2008.

¹⁷ See Department Human Services Victoria (2012) "Disability services: Supporting decision making". Version: February 2017

The capacity to decide is specific to each decision. It will fluctuate depending on the current health and stress levels of the person, familiarity with the subject matter, complexity, and any other factors that impact on that person. The person should be supported to enable decision making in a manner that is relevant to that person.

With reference to decisions that are wider than those concerned with agreeing to the terms of engagement with a psychologist, people have the right to learn from experience (they may have had more limited exposure to some situations because of their disability) and have the "dignity of risk" 18, that is, the right to make choices with an element of risk.

People have the right to change their mind, whether due to gathering more information, having second thoughts or because they try a decision and it does not work out. They also have the right for others to respect their decision, regardless of whether or not others agree with their decision. The psychologist should not impose their own values and attitudes on the person.

Defining competence

If competence to give informed consent is being questioned, there are four levels of cognitive abilities commonly distinguished:19

- 1. The ability to make a clear and stable choice between alternatives.
- 2. An ability to understand the treatment or research being proposed.
- 3. The ability to make a reasoned judgement.
- 4. The ability to understand the context and consequences of the decision.

Optimally, the client grasps the condition and the nature of the intervention or service proposed, understands the procedure and any risks/benefits identified, and is able to make a reasoned and considered informed consent decision. Competence requires the individual to understand the relevant information, appreciate the significance of the information in one's own situation, and to demonstrate reasoning by considering alternatives and then to be able to express choice. The psychologist may have to make a judgement call, and then document the basis for that decision.

Those who are impaired

Impairment in ability to comprehend the purpose and therefore to give informed consent may arise from intellectual disability, cognitive decline due to old age, psychosis, head injury, or any other mental disability. Even where a person is considered impaired, they should be given the information and supported to participate in giving consent to the extent that they are capable. The presence of a support person, advocate, or carer may assist the process of informing the subject of the service but care should be taken to ensure that the third party does not inadvertently coerce or impose their will over the subject with regard to participating in the assessment or receiving treatment.

Cognitive decline in the elderly

"Optimizing the potential for decision-making in persons with dementia contributes to the maintenance of identity, well-being, and quality of life in addition to promoting dignity, integrity, and personhood". 20 The individual's capacity to understand and reason may fluctuate for a person suffering cognitive decline. Decisions vary in complexity and it is more feasible to determine decision-specific competence rather than global judgements of competence. The ability to value and experience is independent of cognition and may guide preferences when the capacity to understand is reduced. Stating information and alternatives in a structured and concrete manner may assist. Involvement of the trusted others to whom the dementia sufferer has delegated authority and decision making may help ensure advocacy of the values and preferences on behalf of that person. The trusted other person may also be familiar with more skilled ways of presenting information to promote participation in decision-making. This person may have a "power of attorney" role.

¹⁸ See Department Human Services (2012).

¹⁹ See Knight, R. and Linscott, R. (2007).

 $^{^{20}}$ See Smebye, K., Kirkevold, M., and Engedal, K. (2012).

If there is more than one session with a person, the process of giving information and gaining consent may need to be repeated as cognitive competence and recall is likely to fluctuate.

Intellectual disability

Although a client may have diminished competence, an attempt should still be made to explain and inform the client in terms that they can understand. A person with diminished capacity to comprehend, such as persons with intellectual or neurological disability, may be more susceptible to suggestions from authority figures than those without such disabilities. Where the individual has experienced dependence with limited choice or control in their life, their capacity to consent may be constrained. Despite these barriers, it remains best practice to involve the individual to the extent that is possible. Participation may be promoted by presenting information in a format that is more amenable to being understood, breaking down the process into small steps, setting clear goals, and discussing the goals regularly. It may be helpful to present the information in various forms, for example, by laying out the options visually. After a decision has been made, it may be helpful to check back that the person remains happy with that choice and to give the option of changing his or her mind.

Consent from an authorised other person

In some circumstances, a legally authorised proxy or support person may provide consent on the client's behalf. For an adult who is deemed not competent, this must be a Welfare Guardian or Enduring Power of Attorney who holds Power of Attorney (in accordance with the Protection of Personal Property Rights Act 1988). For a child who is deemed not competent, it is the parents or guardians who can provide consent (in accordance with the Guardianship Act).

Where consent cannot be obtained due to incapacity or lack of proxy

The psychologist has an ethical duty to take particular care to act in the client's best interests given the extraordinary vulnerabilities inherent in such an engagement. In the absence of consent from the recipient directly or via an authorised proxy, in order to proceed the psychologist must be sure (prescribed by the HDC Code Right 7(4)) that the proposed service safeguards the well-being of the recipient, that reasonable efforts have been made to ascertain the views of that person, and that there are reasonable grounds for believing that the recipient is likely to have consented if they had been competent to do so. The grounds for holding such beliefs must be recorded. The "duty of care" requires the psychologist "to ensure evidence-based practice is followed in the best interest of the client, using the least restrictive option, with the best quality of life outcome". 22 Other available persons who have an interest in the welfare of that person, such as family members, should also be consulted.

Compulsory assessment and treatment under the Mental Health Act

A person deemed to be mentally disordered may lose the right to give informed consent and may be required to undertake psychiatric assessment and treatment in accordance with the Mental Health (Compulsory Assessment and Treatment) Act 1992. Within the first month of an order being issued, the patient may be required to undertake assessment and treatment as ordered by the responsible clinician, whether or not the person has consented. After the first month, the patient may withdraw consent for treatment. However, this lack of consent may be over-ruled if an independent psychiatrist appointed by the Review Tribunal deems that it is in the best interests of the patient to receive treatment and that the anticipated benefit outweighs the patient's rights.

Other court-ordered processes

Assessment may be ordered by the court in accordance with other laws, including the Children, Young Persons and Families Act 1889, the Corrections Act 2004, and the Criminal Procedure (Mentally Impaired Persons) Act 2003.

Recording

Recording consent

The informed consent process used in any professional engagement should be transparently evident in the records arising. This may be covered by a standard consent form which states the generic terms of engagement and is signed by the client. Preferably the records should include the discussion notes which summarise the information given and what the client has

²¹ See Webb, O., Verhoeven, M., and Eggleston, E. (2007).

²² See Webb, O., Verhoeven, M., and Eggleston, E. (2007).

agreed to. Any revisions to the consent content or terms should also be recorded so that there is an evolving report in the file or records with regard to what has been agreed and the terms of engagement.

Confidentiality constraints

The consent discussion should include the client being informed of any confidentiality or security constraints and who would (or could) have access to information held on file. This includes informing the client that professional supervision occurs, which means that client information is routinely discussed for quality assurance purposes. The name of the supervisor should be disclosed to the client. Even though the psychologist may not name clients when discussing with the supervisor, the circumstances of the client may be recognisable should the client and supervisor be acquainted. Informing the client also may include noting the storage systems used for sensitive information. If a video or other recording is taken or a one-way screen is used, explicit consent for this procedure must be gained. In this situation the psychologist should explain why this is necessary and what will be done with any recording that arises.

Release of information

Written consent should be obtained for any release of information to a third party. Where there is a report being prepared for a third party, it may be appropriate to inform the subject of the report of any likely or possible consequences arising. The subject should be told if he or she is considered eligible to receive a copy of the report.

Reviewing consent decisions

The freedom to decline or withdraw consent

In all scenarios the client should feel free to decline and, if they do, any negative effects of that choice should be minimised as much as possible. Furthermore, the client may withdraw earlier consent at any stage of the engagement.

Revision of the informed consent

Any significant change in the nature of the service signals a need to re-visit informed consent. Any indication that the client has changed his or her mind would also signal a need to revise the consent.

Establishing a culture of openness

The client should be encouraged to ask questions and raise any concerns so that open and honest communication is established. It protects the dignity of the client and makes explicit their autonomy within the power imbalance that is inherent in the consultation setting.

Objectives may change

In a mental health or counselling consultation, initial information may need to be stated in general terms with an expectation that clarification will be offered as fuller assessment information comes to hand. An intervention that is to be adapted as information is gathered may be described as a general strategy or approach rather than specified in detailed terms.

Research participation

Consenting to research participation

The Nuremburg Code of Ethical Practice 1949 established in international law that human subjects of research must give their voluntary consent based on information about the research study, the risks arising, and the potential benefits. In practice this means that full disclosure of the intentions of the study is required. Research subjects who have consented must also be made aware of their right to withdraw at any time.

The Cartwright report which was developed by the Committee of Inquiry (1988) has been influential in establishing the principles that all research should be reviewed by an ethics committee and that the informed consent of participants must be recorded in writing. The recommendations of the Committee led to the Health and Disability Commissioner Act 1994, the appointment of the Commissioner, and the establishment of the Code of Rights, which also has implications for the ethical treatment of participants in health and disability research.²³ The

²³ See Chamberlain, K. (2007). Version: February 2017

_

Privacy Act 1993 does not allow information collected for one purpose to be used for another (unless the data collected could not be reasonably connected to any individual).

The National Ethics Advisory Committee is a statutory committee charged with determining nationally consistent ethical standards across the health sector (in accordance with section 16 of the New Zealand Public Health and Disability (**NZPHD**) Act 2000). The Committee has issued ethical guidelines for intervention studies and observational research for the health and disability sector, including the issue of informed consent. The NZPHD Act formally established regional Health and Disability Ethics Committees.

Clauses 1.7.8 and 2.6.2 of the Code of Ethics require psychologist researchers to ensure that "the procedures and information provided meet the standards of a relevant human subjects' ethics committee". There is a moral and ethical requirement for all research proposals involving human subjects to be approved by an ethics committee prior to commencement. This may involve seeking approval through the regional committees referred to above or one of the Institutional Ethics Committees (usually under the auspices of a university).

If the client is requested to participate in a research study, the nature of the research activity should be defined, it should be confirmed that the study has gained ethics approval (and by what committee), and the potential theoretical gains arising from the research described. The information provided should be in writing and the consent formally recorded. Consent should be voluntary, without coercion and, if consent is withheld, there must be no negative consequences arising.

Children in research study

If a psychologist researcher wishes to proceed with research involving children, that practitioner is advised to discuss the planned research with an ethics committee and legal advisors. The principle to be applied is that any risks must not outweigh the anticipated benefits. Parents and guardians can give permission for a child to be involved in a research study if the child has been given information and has assented to involvement. A competent child could give consent on their own behalf.

Practising on the internet

There are additional issues to address when delivering services through the internet.²⁴ In addition to describing the services that they anticipate delivering, the psychologist must explain the procedures and policies that will guide telecommunications. There may be additional challenges posed by cultural, linguistic, and time zone differences. There may be laws and regulations which obligate health service providers to meet certain requirements in the country where the client resides. The telecommunication technology may raise additional risks to the client's information in transit and arising out of electronic storage systems. The client should be informed about how the data will be stored, who may access it, and how the security of the data will be protected.

Informed consent should be in writing and may include details of how telecommunications will be used, the boundaries that will be established and used, and the procedures for responding to electronic communications. The principles to determine charging for services should also be established in advance. Any risks associated with the electronic communication should be identified in advance (to the extent possible) and information given as to how those risks will be managed.

²⁴ See the New Zealand Psychologists Board's best practice guidelines on "The Practice of Telepsychology". Version: February 2017

References

Ancel, G. (2012) Information needs of cancer patients: A comparison of nurses' and patients' perceptions. J Canc Educ, vol 27, pg 631-640.

Cargo, T., Waitoki, W., and Feather, J. (2016) Informed consent in the Aotearoa New Zealand context. In "Professional Practice of Psychology in Aotearoa New Zealand, 3rd edition" edited by Waitoki, W., Feather, J., Robertson, N. and Rucklidge, J. Published by the New Zealand Psychological Society: Te Ropu Matai Hinengaro o Aotearoa, Wellington.

Chamberlain, K. (2007) Research ethics and the protection of human participants. In "Professional Practice of Psychology in Aotearoa New Zealand" edited by Evans, I., Rucklidge, J., and O'Driscoll, M. (2007) Published by the New Zealand Psychological Society: Te Ropu Matai Hinengaro o Aotearoa, Wellington.

College of Alberta Psychologists (2008) Informed consent: Ethical guidelines, principles and standards.

College of Alberta Psychologists (Adopted 2001, revised 2010) "Limits to confidentiality and consent for services: Special issues in working with minors".

Cooper, E. and Rickard, S. (2016) "Healing whānau violence: A love story" in "Te Manu Kai i Te Mātauranga: Indigenous psychology in Aotearoa/New Zealand" edited by Waitoki, W. and Levy, M. (2016) Published by the New Zealand Psychological Society, Wellington.

Department of Human Services, Victoria (2012) "Disability services: Supporting decision making: A guide to supporting people with a disability make their own decisions". Published by Victorian Government Department of Human Services, Melbourne. Downloaded www.dhs.vic.gov.au

Dudley, M (2016) "Māori and Neuropsychological Assessment" in "Te Manu Kai i Te Mātauranga: Indigenous psychology in Aotearoa/New Zealand" edited by Waitoki, W. and Levy, M. (2016) Published by the New Zealand Psychological Society, Wellington.

Gilgen, M. and Stephens, M. (2016) "Whanaungatanga: Asking who you are: Not, what you are" in "Te Manu Kai i Te Mātauranga: Indigenous psychology in Aotearoa/New Zealand" edited by Waitoki, W. and Levy, M. (2016) Published by the New Zealand Psychological Society, Wellington.

Hall, D., Prochazka, A. and Fink, A. (2012) "Informed consent for clinical treatment". Canadian Medical Association Journal, 184(5), pg 533-540.

HDC "Fact sheet- Consent for consumers who are not competent". Downloaded website 6 November 2013.

Knight, R and Linscott, R. (2007) Informed consent in research and clinical practice with adults. In "Professional Practice of Psychology in Aotearoa New Zealand" edited by Evans, I., Rucklidge, J., and O'Driscoll, M. (2007) Published by the New Zealand Psychological Society: Te Ropu Matai Hinengaro o Aotearoa, Wellington.

Medical Council of New Zealand (2011) Information, choice of treatment and informed consent. www.mcnz.org.nz

Ministry of Health (1998) Consent in child and youth health: Information for practitioners. Ministry of Health, Wellington. www.moh.govt.nz

Rucklidge, J. and Williams, T. (2007) Working with children and youth: Issues of consent. In "Professional Practice of Psychology in Aotearoa New Zealand" edited by Evans, I., Rucklidge, J., and O'Driscoll, M. (2007) Published by the New Zealand Psychological Society: Te Ropu Matai Hinengaro o Aotearoa, Wellington.

The British Psychological Society (2008) Generic Professional Practice Guidelines. www.bps.org.uk

Smebye, K., Kirkevold, M. and Engedal, K. (2012) How do persons with dementia participate in decision making relate dot health and daily care? A multi-case study. Health Services Research, vol 12, pg 241. http://www.biomedcentral.com/1472-6963/12/241

Taylor, J., Dickson, J., Rucklidge, J., and Williams, T. (in press 2016) Confidentiality and Privacy. In "Professional Practice of Psychology in Aotearoa New Zealand" second edition. Published by the New Zealand Psychological Society: Te Ropu Matai Hinengaro o Aotearoa, Wellington.

Webb, O., Verhoeven, M. and Eggleston, E. (2007) Principles of psychological work with people with intellectual disabilities. In "Professional Practice of Psychology in Aotearoa New Zealand" edited by Evans, I., Rucklidge, J., and O'Driscoll, M. (2007) Published by the New Zealand Psychological Society: Te Ropu Matai Hinengaro o Aotearoa, Wellington.

Wilson, N., Tamatea, A. and Riley, D, (2007) Psychology in a criminal justice context: Principles and interventions. In "Professional Practice of Psychology in Aotearoa New Zealand" edited by Evans, I., Rucklidge, J., and O'Driscoll, M. (2007) Published by the New Zealand Psychological Society: Te Ropu Matai Hinengaro o Aotearoa, Wellington.