

What makes a child a 'competent' child?

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ABSTRACT

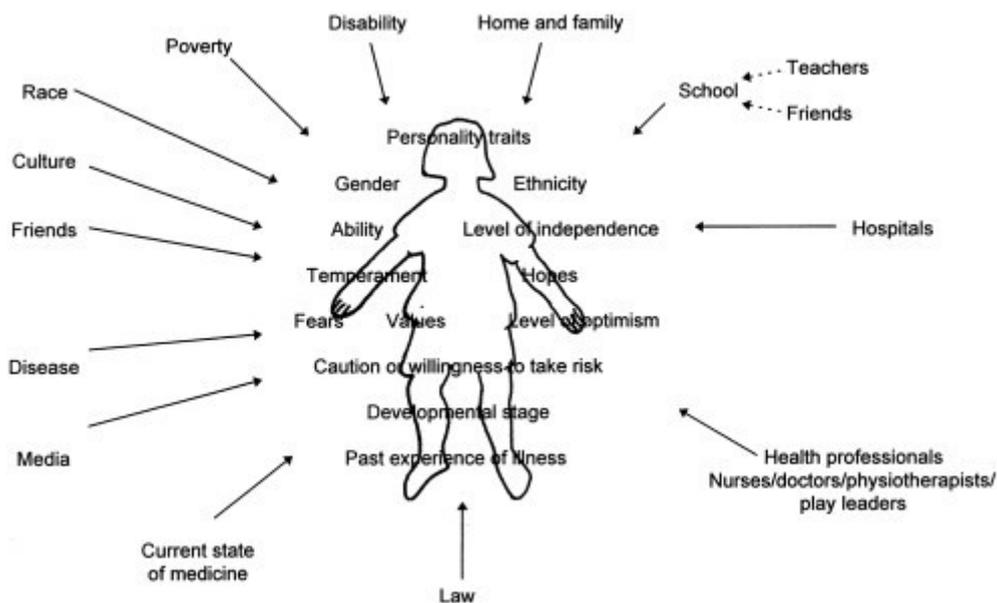
Competence is a vital component of the informed consent process. The perceived level of a child's competence may influence their degree of participation in health decisions that affect them. It is the responsibility of the health professional to gauge a child's level of competence. Child competence, however, is not a static attribute that is linked to age. Rather, it is dynamic, changing in nature and dependent on a child's previous experiences, personal attributes, network of relationships around them and cultural and environmental context. Consequently, there is no single verified assessment tool to assist in the recognition of competence for New Zealand children. Adding to this complexity are the unclear interpretations of New Zealand health legislation and policy regarding whether or not a child can legally consent or refuse healthcare advice and treatment without the consent of a legal guardian. Under the Care of Children Act 2004 and the Code of Health and Disability Services Consumers' Rights 1996, the Health and Disability Commissioner¹ states "a child may consent themselves [to health treatment] if and when the child achieves sufficient understanding and maturity to understand fully what is proposed". This paper poses the question: What is 'competency' and how is this decided? For the purpose of this article, 'child' pertains to those under the age of 16 years.

The threshold for child competence to consent to health care treatment in New Zealand remains ambiguous. Although not clearly stated, New Zealand law infers that children under the age of 16 years may give or withhold consent to healthcare treatment, so long as they are competent to do so.^{1,2} Currently, it is the role of the healthcare professional to decide whether or not a child has adequate competence, which according to the Health and Disability Commissioner, is the time at which a child achieves sufficient understanding and maturity to fully comprehend the proposed treatment.¹ Upholding a child's decision through the informed consent process is one way of ensuring children's rights to participation and autonomy are respected. However, competence is not only a legal concept, it is also the degree to which health professionals allow children to participate in matters that are important to them.

The process of informed consent, as explained by the Ministry of Health,³ obligates health professionals to acknowledge and respect a health consumer's right to autonomy. The main principles underlying

informed consent are effective communication of full information, based on the voluntary choice of a competent person.³ To make competent decisions, children require age appropriate information that supports their health literacy and the opportunity to participate.⁴ Children's competence is defined by Alderson⁵ as "more than a skill, it is a way of relating and can be understood more clearly when each child's inner qualities are seen within a network of relationships and cultural influences". Recognising competent children not only supports ethical arguments regarding respect for children's rights and their personhood; it has other more tangible benefits to both the child and healthcare services. These include improved treatment adherence, clinical effectiveness, disease prevention and delivery of health services.⁶⁻⁹ Secondary benefits include children learning to advocate and take responsibility for their own health, and the enhancement of their personal development and participation in society.^{8,10}

The multiple benefits of involving and respecting competent children in decision

Figure 1: Internal and external influences on children's competence to give informed consent.^{5,24}

making may be evident, however the act of identifying competent children is complex and fraught with difficulties. First and foremost, competence is a dynamic state rather than a fixed attribute that a child either does or does not possess.

There are multiple internal and external factors that influence the state of a child's competence. Some internal factors include prior experiences of illness,¹¹ level of independence, ethnicity and temperament.¹² External factors include the environment in which competence is assessed¹² and the manner and form in which information is imparted.^{3,13-18} Changes in social and cultural contexts,¹⁹ media representation, and family and health professional support can also have an impact on a child's level of competence.^{4,5,8,11,12,20} Culture may dictate the manner by which health professionals impart information and conduct the informed consent process. The interface between different cultural worldviews of health professionals, children, and the children's family may bring about opportunities for misunderstandings. On a practical basis, Brook (2000)¹⁶ acknowledges that competence is difficult to define, assess and measure.

Recommendations for improving New Zealand children's participation in society and health decisions were given by the UN Committee on the Rights of the Child (CRC) in 1997, however the UNCRC Monitoring Group determined that the level of children's participation has not progressed.²¹ The UNCRC Monitoring Group has representatives from non-governmental

organisations and representatives from two Independent Crown entities, the Office of the Children's Commissioner and the Human Rights Commission. The report 'Kids Missing Out',¹⁹ released by UNICEF in December, 2013, was a stocktake of New Zealand's progress on implementing United Nations Convention on the Rights of the Child (UNCRC). It stated:

Initiatives to allow children to have a say in matters that affect them have not always been sustained, there are very few processes for eliciting children's views on legislative and policy development, and children's ability to participate in judicial and administrative proceedings is variable.

Child participation is also recognised by the Human Rights Commission in the National Plan of Action for the Promotion and Protection of Human Rights (NPA),²² which was due to be completed in June 2015. Taking into account the opinions of children in the Children's Symposium 2003, the NPA acknowledged that children need to be listened to, have their opinions given due weight and have their participation rights under UNCRC implemented.²³ The NPA suggested the creation of a program to improve children's participation in governmental and non-governmental sectors, including educational resources to assist organisations to involve children in decision making.²³

What is 'competency'?

Children's competence is not a fixed state but is dynamic; their ability to understand

develops and modifies with their experiences and changes in their social contexts.¹² In addition, children's competency may be recognised, denied, encouraged or inhibited.^{11,12} Whether children's choices are honoured may be dependent upon the supporting adults' willingness to supportively, generously and courageously respect children's decisions.^{11,12} Figure 1, described by Alderson (1992)⁵ and illustrated by Orr (1999),²⁴ aptly depicts the myriad of internal and external variants that may influence a child's competency. Although it fails to include facets specific to the health care environment, such as life experience, nature of information and its delivery, and opportunity to participate, it provides a concise description of intrinsic and extrinsic factors that may affect a child's level of competency.

Age has been shown to be an inaccurate marker of the level of children's competence.^{12,25} Whereas children's experiences, both in general life adversities and in illness, have been found to more greatly influence their capacity to give informed consent.^{11,12} The ability of children to develop health literacy and demonstrate competence is impacted by additional factors such as the use of technical language and the pace at which information is imparted. It is the responsibility of health professionals to impart information in a way that supports children developing health literacy. This influences a child's ability to process and understand their conditions and options. In addition, the environment in which the information is given may also have an effect, for example the unfamiliar hospital ward environment versus the community setting. The time a child has to digest and understand the information is another relevant factor (and may be a barrier to obtaining meaningful consent in an acute setting).

Different cultural constructions of childhood, the family, and healthcare settings may influence the manner and form of information imparted, as well as the manner by which it is interpreted.³ For example, the Anglo-European emphasis on individual autonomy may conflict with the Māori value of wholeness and collectivity. Many Māori tamariki (children) may not only belong to mātua (parents)

but to kaumātua and kuia (grandparents) and tīpuna (ancestors); they are a part of a whānau, hapū (extended family) and iwi (tribe), and they belong to the whenua (land).³ Consequently, when a child is faced with a health decision, so may be the whānau and hapū, rather than the simple dyad of parent and child, which is frequently the focus of Anglo-European approaches. A Māori child's competence may be influenced if they are approached on individual terms rather than receiving support in a more collective manner.³ The collective approach may also be applicable to many Pacific children. Pacific families come from 22 different countries, all varying in their use of the English language, and their involvement in church and other supporting groups.³ Many Māori and Pacific children are part of a large extended family and community; their wellbeing is contingent on their integration and on the community's overall wellbeing.³ However, it is important to also acknowledge that diversity exists within the collectivism approach for many contemporary Māori and Pacific Island families. The Charter on the Rights of Tamariki Children and Rangatahi Young People in Healthcare Services in Aotearoa New Zealand²⁶ supports the rights as set out by UNCRC and that children's health status based on tino rangatiratanga and te Tiriti o Waitangi are a vital ingredient for the provision of health services to Māori children. A child's culture and local ecosystem need to be taken into consideration by health professionals who are attempting to understand a child's experiences, capabilities and perspectives.²⁷ Kawa whakaruruhau (cultural safety) is an important aspect of these considerations, which require an understanding and acceptance of cultural differences.

Why is it important to recognise competent children?

It has been observed that respecting children's involvement in health care decision-making contributes to the improvement in their health status.³ Doyle, Lennox, and Bell⁹ presented this view in their systematic review, which positively associated patients' experiences with

patient safety and clinical effectiveness. Involvement in healthcare decisions and respect for patients' preferences were two of four relational aspects used to measure patients' experiences.⁹ A positive association was then found between patients' experiences and adherence to recommended medication and treatments, preventative care, healthcare resource use and technical quality-of-care delivery.⁹ Coyne and Gallagher utilised similar definitions for children's experiences in healthcare settings. They identified that children who were involved in the decision making process had mostly positive experiences and that the process helped them prepare for what to expect, reduced their anxieties, and provided reassurance.⁸ Consequently, the recognition of children's capacities and their involvement in decision making is an integral part of their healthcare experience, and in turn patient safety and clinical effectiveness.

Children's views of their healthcare experiences provides vital information.⁷ There is a dearth of research regarding their views of health services and existing research is often from adult proxy decision-makers.⁷ In particular, the views of younger children were rarely sought, despite growing evidence of their competence to provide valuable contributions to healthcare service improvement.⁷ Health professionals may gain a true representation of children's needs by directly seeking their feedback.

Listening to children and respecting their opinions can contribute to a child's personal development. This support can lead to children making better decisions which can lead to improved health outcomes.¹⁰ It may prepare them to participate in society and strengthen their accountability.¹⁰ Allowing children to have an active role in their healthcare decisions teaches them in an incremental process rather than having instantaneous responsibility at the age of sixteen.²⁸ Treatment is more likely to be effective if children are allowed to take part in the decision making and for their contributions to be respected; alternatively, children who feel coerced into medical treatment tend to recover more slowly.^{6,12,28}

What is known about New Zealand health law and policy with regard to child competency?

Children's competence to consent in New Zealand is regulated by the Code of Health and Disability Services Consumers' Rights 1996 (the Code)²⁹ and the Care of Children Act 2004.³⁰ It is also influenced by foreign case law, most notably the Gillick case,³¹ and also the UNCRC³², which introduced the notion of diminishing parental responsibility with the evolving capacity of the child. The Ministry of Health³ discussed this notion as the 'maturity approach', which may be contrasted with the 'status approach' in which the age of the child is determinative.³⁰

The 1985 landmark English case of *Gillick vs West Norfolk and Wisbech AHA*³¹ was significant because it marked the emergence of the 'competent child' discourse. It recognised that children can be independent, autonomous, and competent decision makers with regards to their health care. It challenged the ideology of parenting being a right, or a dominant and controlling process in a child's life, to being a responsibility and duty.³³ This case is a clear rejection of the 'status based'³ approach, where a set age limit dictates the competency of a person.¹⁷ The House of Lords ruled that parental rights to decide whether or not their child receives medical treatment cease when the child reaches sufficient maturity and has the understanding and intelligence to make an informed decision.³⁴ The Ministry of Health,³ Medical Council of New Zealand³⁵ and Health and Disability Commissioner¹ all indicated their growing support for the maturity based approach,³ which supports the applicability of the Gillick case to the New Zealand context.

Unfortunately, there has been little guidance as to what Gillick competence actually is, and when or how it can be applied in New Zealand.³² This leaves a grey and ill-defined area for New Zealand courts, and an ethically challenging set of principles for health professionals.³²

United Nations Convention on the Rights of the Child

The seminal document UNCRC,³² ratified by New Zealand in 1993, obligates health professionals to ensure children's voices are heard and given due weight in accordance with their level of maturity. However, the notion of 'the child's best interests' described in Article 3 of UNCRC overrides children's rights of self-determination, freedom of expression (Article 13), and respect for their views (Article 12).³²

The Code of Health and Disability Services Consumers' Rights 1996

New Zealand is unique in that the Code presumes all consumers of healthcare to be competent.¹⁷ Right 7(2) states, "Every consumer must be presumed competent to make an informed choice and give informed consent, unless there are reasonable grounds for believing that the consumer is not competent".²⁹ Right 7(7) addresses refusal of consent by stating, "Every consumer has the right to refuse services and to withdraw consent to services".²⁹ 'Consumer' has been defined as a health or disability services consumer and does not exclude children. Although not directly supporting the maturity-based approach, the presumption of competence rejects the status-based approach.

Care of Children Act 2004

In contrast to the Code, the Care of Children Act 2004 (s36) refers to age—a status-based approach.^{3,35} The Act is less clear regarding people under 16 years of age compared to those over 16 years of age. This is despite there being a large number of submissions on the Care of Children Bill recommending clarification on the issue and proposing adoption of the rule of 'evolving capacities' in line with the Gillick case.¹⁸ The abstruseness and inconsistencies in these governing documents leaves health professionals with little clarity about how to effectively assess competence and build it into the fabric of interactions with children. In 2006, Professor Skegg² reported on the status of consent by competent children in New Zealand:

Given the indecisive and conflicting High Court decisions, the matter is not entirely free from doubt. Never-

theless, the better view is that minors' common law capacity to consent to medical treatment has not been extinguished by the New Zealand legislation, and that the consent of those under the age of 16 will sometimes be effective in law, be it for the purpose of the criminal law, the law of torts, or the Code of Rights.

Thus, New Zealand awaits further detailed legal guidance.

The Medical Council of New Zealand

The Medical Council of New Zealand (MCNZ) supports the assessment of a child's competency to give informed consent. The MCNZ's guidance, contained in *Information, Choice of Treatment and Informed Consent 2011*, described a competent child as an individual who "is able to understand the nature, purpose and possible consequences of the proposed investigation or treatment, as well as the consequences of non-treatment".³⁵ However, at present there is a paucity of research evidencing how health professionals put this advice into practice and conduct their assessment of child competence to consent. The MCNZ recognised the lack of direction on the subject from the Care of Children Act 2004.³⁵ It stated:

It is not clear whether parental consent is always necessary for medical treatment or procedures for persons under 16 years. Section 36 [of COCA] does not automatically prohibit persons under 16 years from consenting to medical, surgical or dental procedures. In the absence of clear legislative direction it is likely that the principles laid out in Gillick, namely that parental consent is not always necessary for medical procedures or treatment for persons under 16 years, will be followed by New Zealand courts.

Deciding competency

Currently, no solitary assessment tool is applied to assess children's competence in New Zealand. Rather, it is a judgment made by health professionals based on legal guidance from the Ministry of Health³ and the Medical Council of New Zealand.³⁵ The context in which the healthcare decision

is to be made, for example the acuteness of the child's illness, the complexity of the information and the available time for a decision to be made, might also influence a healthcare professional's assessment of a child's level of competency.³

A number of screening tools and frameworks have been developed in an attempt to standardise the assessment of competence. One of the more recent screening tools was developed in 1998 by Billick et al,³⁶ who conducted the Competency Questionnaire-Child Psychiatric (CQ-ChP) test which evaluated 25 inpatient children for competency, and utilised the Wechsler Intelligence Scale for Children-Revised Edition (WISC-R). The main aim of this test was to identify an age at which competency was achieved. The mean age of competency was found to be 10.1 years with participants showing a year 6/7 (10 to 11 years old) reading level.³⁶ However, the authors concluded it was not possible to correlate competency with an age.³⁶ In 2001, the CQ-ChP test was revised as the Competency Questionnaire-Pediatric Outpatient Modified Version (CQ-Peds), which consisted of 19 items and emphasised the developmental aspect of competence in children.³⁷ Again, an age at which competency was achieved could not be determined.³⁷

The document, *Consent in Child and Youth Health: Information for Practitioners* by the Ministry of Health, 1998,³ indicated the provisions for a child to be deemed competent. It stated:

Regardless of age, to be deemed competent an individual must be able to understand that they have a choice (freedom from coercion), why they are being offered the 'treatment', what is involved in what they are being offered, and what the probable benefits, risks, side effects, failure rates and alternatives are.

Although it pre-dates the Care of Children Act 2004, it is consistent with instructions

from the MCNZ that state the importance of understanding the nature and purpose of the treatment and its consequences.³⁵ Lord Scarman and Lord Fraser, from the Gillick case, stated the need for sufficient understanding and intelligence.³¹ Hence, healthcare professionals are required to make case-by-case judgements on the level of perceived competence a child possesses, which in turn may affect the child's level of involvement in healthcare decisions.

Conclusion

Competence is not a rigid dichotomy between competent or incompetent, but rather a dynamic continuum. The evolving nature of competence makes it difficult to state a simple set of rules or attributes a child requires in order to be deemed competent. The importance of recognising competent children and giving their views due weight may be clear, however the act of identifying who is competent and who is not is complex. The inconsistent alignment of New Zealand health legislation and policies further obscures this process. However, the UNCRC and the Charter challenge us to seek greater participation and decision power sharing with children.

This article highlights the need for further action from both academic and governmental agencies to address the issues faced in determining the competence of children to make health decisions. An exploration of the key attributes of child competence is required to assist health professionals in the identification of competent children, which should inform more clear and practical policies on the subject. This paper provides the basis for further research by the authors to include a definition of child competence relevant to the New Zealand health context, a tool to assist health professionals to identify competence attributes in children and professional development programs for health professionals to support the participation of children in health care.

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