

The measles outbreak and your right to information

As New Zealand grapples with a measles outbreak, questions are being asked about the role of 'anti-vaxxers'. The government is attempting to contain the disease as concerns grow about it spreading to the Pacific, New Zealand may be losing "herd immunity" and our elimination status with the WHO is at risk.

So who are the 'anti-vaxxers'? And how do their arguments relate to the Code of Health and Disability Services Consumers' Rights (the Code), which entitles people to make informed decisions about their care?

Anti-vaxxer is a term used to describe those who do not accept the value of vaccinations for diseases like measles. They hold these beliefs for a range of reasons and many believe that vaccinations cause serious harm. Anti-vaccination groups advocate for the body's natural immunity and sometimes for alternative therapies such as high dose vitamin C treatment and other 'complementary and alternative medicines' such as naturopathy and homeopathy. Some of these groups argue that their position is supported by the Code as health consumers are entitled to make informed decisions about their own care and have the right to reject preventative procedures such as vaccination.

So how do the rights in the Code impact on those who wish to advocate against vaccinations?

The Code was developed as a result of the Cartwright Inquiry into National Women's Hospital. The Inquiry took place because women with carcinoma-in-situ were included in an experiment in which they were deprived of conventional treatment – without their knowledge or consent. Any person offering education or advice on vaccination to health consumers is likely to be subject to the Code, though individual cases must be assessed in their factual context. It is not necessary to be a registered health professional to be subject to the Code.

Informed consent is at the very heart of the Code. Right 7 of the Code states that every consumer has the right to make an informed choice and give informed consent to treatment. Right 7(7) provides that every consumer has the right to refuse services and withdraw consent to services. "Consumer" includes a person entitled to give consent on behalf of a consumer who cannot consent for him or herself - such as a child. In New Zealand parents / guardians have the right to make informed choices, give informed consent and refuse to give consent on behalf of their children until the children have the capacity to make choices for themselves.

But to enable people to give truly informed consent or refusal of consent, they must have accurate information. Right 6 of the Code states that every consumer is entitled to the information that a reasonable person, in their shoes, would want *before* making a decision. Right 6(1)(b) states that consumers must be given an explanation of the options available including an assessment of the expected risks, side effects, benefits and costs of each option. It is self evident that the information provided must be accurate, balanced and unbiased. Which leads to the question, what information would a reasonable parent want before making an informed decision on whether to vaccinate their child for measles?

People are entitled to an overview of the current scientific evidence for vaccination and the risks and benefits of vaccinating. Importantly, educators and providers must also outline the risks and benefits

of *not* vaccinating. People have the right to be informed, of the extent to which the education or advice provided to them, is consistent with conventional theories of medicine and has, or does not have, the support of the majority of health practitioners. Consumers should also be advised of conventional treatment options, the evidence base for those options, their risks, benefits and efficacy, as reflected by current knowledge.

So long as individuals or groups who subscribe to the 'anti-vax' movement comply with the requirements set out above, they are entitled to provide information from the perspective of their own practice and beliefs. It is crucial, however, that if the position being put forward to the consumer is at odds with the current scientific consensus, that must be made explicitly clear. Anti-vax groups cannot misrepresent the scientific evidence either. For example, there is no scientific basis for the belief that there is a link between autism and the MMR vaccine.

The current scientific / medical consensus favours vaccination and notes that a failure to vaccinate increases the chances of getting measles with its various consequences, some of which are very serious indeed. While it is not necessary for providers to agree with the consensus view, they must not withhold that information from consumers. They must make it clear when their position diverges from the scientific consensus.

The Code gives rights to all consumers – those who subscribe to conventional medicine and those who do not; those who wish to vaccinate and those who don't. Applying the principles outlined above, the Code places obligations on providers of conventional and alternative medicine to ensure that consumers are fully informed and thus able to provide informed consent.

I urge all parents and consumers to speak to their primary health care provider for information about the current measles outbreak and seek urgent attention if they are concerned about themselves or their loved ones.

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