

Could parental refusal of newborn screening be overridden by a court?

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Series Editor

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Some parents do not give their consent for routine screening of their newborn by heel prick blood tests. This issue has not yet come before the courts in Australia but if it did, could the courts override the parents' decision?

It is routine practice in all jurisdictions in Australia to screen newborn infants for certain genetic conditions by a heel prick blood test (Guthrie test) a few days after birth. However, testing is not compulsory here, nor in New Zealand or the United Kingdom, unlike in the USA. This means that parents in Australia are legally entitled to refuse permission for their child to be tested (although, as explained later, that refusal could be challenged in a court). Without parental consent, or other lawful authority, taking blood for testing would constitute a battery (trespass to the person, colloquially called 'assault'), for which the parents could sue the person taking blood and his or her employer.

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A heel prick blood test is a minimal invasion of the child's body and the potential advantages of early screening are generally believed to be considerable, so the question arises as to whether parental refusal could be overridden by a court order authorising the test in the child's 'best interests'.

Advantages of newborn screening

The conditions for which newborn infants are routinely screened vary slightly between jurisdictions. All States screen for phenylketonuria (PKU) and hyperthyroidism, all States except Victoria screen for galactosaemia, and all States except Tasmania screen for cystic fibrosis. Although these conditions are not curable, effective interventions are available. For example, early detection of PKU means the child can be put on a special diet and hence avoid the severe mental retardation that would otherwise result.

Heel prick blood tests are cheap and accurate, and the means by which the blood samples are obtained are relatively noninvasive. However, they are not without a down side. The child cannot, of course, be involved in the decision making, and the tests may reveal information

the child may in later life prefer not to have for reasons such as employment and insurance. This is of limited relevance at present, perhaps, when only a few conditions are tested for routinely in neonates and nonroutine testing is only done when there is a clear medical reason. In the future, however, many tests may be conducted routinely on heel prick blood samples. Already, screening for 30 conditions is possible with random mass spectrometry techniques, and the number may be increased to hundreds when 'gene chip' technology becomes widely available.

A more important objection to neonatal screening is the retention and potential use of samples after the test has been done.^{1,2} This raises the additional issue of the need to store the samples, which is outside the scope of this article.

Limits on parents' decisions

Although parents are legally entitled to consent to medical procedures for their child – and also to refuse them – their right to make medical decisions is limited by the requirement that they must act in the child's best interests. If there is doubt whether a parent's decision is in the best interests of the child, any person may



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Taking a blood sample from the heel of a newborn for a Guthrie test.

apply to the court to override the parent's decision. The application may be made either to the Family Court of Australia, under the Family Law Act 1975 (Cwlth), or under State legislation, such as the *Children and Young Persons Act 1987* (Vic).^{3,4} A question then arises as to whether the parent's decision is not in the child's best interests.

To date, there is little relevant case law in Australia. The High Court of Australia ruled in Marion's case that there is sufficient doubt about a sterilisation operation being in the best interests of a patient aged under 18 years that consent cannot be given by the parents alone, and the issue must also be considered by a court.⁵ Later, the Family Court of Australia made a similar ruling in relation to gender reassignment surgery, stating that court approval is also required for that surgery.⁶ In both of these cases, the parents' decision was approved by the court, and was not challenged as being contrary to the child's best interests.

That, however, did not occur in a Victorian case in which parents refused consent for their teenage son to have surgery to correct the transposition of the major vessels to the heart.⁷ Although the boy died before the hearing was completed, the court was inclined to overrule the parental refusal. In an English case, on the other hand, where parents refused consent for a liver transplant for their infant son, the court deferred to the parents' wishes – a decision that was unusual because courts have tended to consider that the maintenance of life is the primary objective of medical care.⁸ In a conjoined twins case, the English Court of Appeal overrode the parents' decision not to operate to separate the twins, saying that one twin should be saved, even though the other one would die, rather than leaving both to die.⁹

Parents' v. the Court's decision

Parental refusal of newborn screening has not yet come before the courts in

Australia, although a number of parents apparently refuse tests each year. However, the matter was recently considered by the Irish High Court and the Supreme Court of Ireland after the North Western Health Board challenged the decision of parents to refuse a test for their infant son.^{10,11} The parents said that it was their 'strong religious belief that nobody is allowed to injure anybody else'. The judge at first instance, and four of the five judges on appeal, found in favour of the parents. There were two main reasons. Firstly, the judge at first instance held that the State should enact legislation if it intended to override parental refusal for testing, and the matter should not be left to the courts. Secondly, both the *Child Care Act 1991* (Ireland) and the Irish Constitution specifically refer to the 'rights and duties of parents'.¹²

If a similar case arose in Australia, the court might well defer to the parents' decision, saying that if the State intends to make neonatal screening mandatory, then Parliament should legislate. The High Court of Australia adopted a similar argument in *Breen v. Williams* (1996) in deciding that patients have no common law right to gain access to their medical records, and if they are to have such a right, Parliament should legislate – which has now been done with the recent amendments to the *Privacy Act 1988* (Cwlth) and *Health Records Act 2001* (Vic).¹³⁻¹⁵

Alternatively, the court might be reluctant to usurp the parents' right to make decisions for their child. Australia has no written Bill of Rights so this view would not be based on a constitutional argument, as in the Irish case. However, it is a principle of Australian law, as it is in other common law countries, that the primary responsibility for child rearing lies with the parents. This principle should not be set aside lightly. Indeed, in a fascinating seminar at Melbourne University earlier this year, visiting UK law academic Professor Derek Morgan questioned the role

of the courts in deciding about treatment in far more life-threatening circumstances. Why should judges make decisions about severing conjoined twins or withdrawing ventilation from patients in a persistent vegetative state rather than doctors, carers and families, he asked. Why should the State interfere with parents' decisions for the upbringing of their child, perhaps undermining the vital relationship between the parents and child?

On the other hand, we know that the State often does intervene where parents are alleged to be a danger to their child. In such cases, the State may even remove the child from the care of the parents. This is the opposite end of a continuum in which parental autonomy is promoted to the greatest extent that is possible while not harming the child.

Conclusion

If the risks of a child developing PKU, hyperthyroidism or cystic fibrosis are relatively remote, a court might well leave the decision of whether to screen soon after birth to the parents, despite the fact that the consequences of missing the opportunity for early intervention are serious.

In my view, however, the interests of the child would be better served by court intervention to override the parents' refusal of neonatal screening. Although the risk of the child suffering one of these conditions is relatively remote, the consequences of missing the opportunity for early intervention are grave. Also, the obtaining of the heel prick blood sample is a minimal invasion, involving only the brief pain of a pinprick and minor discomfort afterwards. Parents who are concerned about the retention of blood samples can request that they be destroyed immediately after screening. If parents are to be given the right to refuse such a procedure, we might wonder whether the cost of recognising parental rights comes at too high a price.

Series Editor's comment

I think Professor Skene has hit the nail firmly on the head. Parents should have a right to object to testing; the States should have the right to test that objection in court.

My concern is broader. Currently, testing is not mandatory but is performed routinely. When recently researching a paper on this topic, I asked a number of new mothers what they had been told about the heel prick test. Some vaguely remembered it being mentioned, in passing, at their antenatal classes. Very few recalled it being mentioned in hospital before the test was performed. There are excellent explanatory pamphlets distributed in each State to hospitals and antenatal clinics by the testing laboratories, but no one in my admittedly very small sample of recent mothers recalled seeing one.

As we keep stressing, the issue is not 'informed consent' but 'informed decision making'. It follows that informed refusal is as important as informed consent. In this instance, from the limited number of cases referenced in the legal literature, 'refusal' appears to have been informed – if one accepts genuinely held religious beliefs as being informed. I suspect, however, that in most cases of heel prick testing, consent for testing was not requested at all, and hence no issue of whether nonconsent was informed could arise.

If the parents know in advance that a test is proposed, how the test is done, what conditions are looked for and what will happen to the test material after testing, they are at least in a position to consider their options. They may be advised that if they refuse consent, a court order may be sought to override their objection, but at least the process is then transparent. Even if the test is mandated by legislation, it should never be performed 'secretly'.

There is a broader issue, as Professor Skene foreshadows, about storage of the

heel prick blood samples. Testing, with post-testing storage of the heel prick blood blots, has been around since the 1960s. Very few of the Australian testing laboratories have destroyed any of the stored blots. How many of us are aware that a DNA database of almost every person born in Australia since the 1960s is potentially available? Does it matter? Indeed, could not this database potentially result in huge benefits to the community? The issue is not the potential risk or benefit from prolonged storage of the blots but that not only are very few parents in Australia given the opportunity to consent or object to testing, very few are given the opportunity to consent or object to prolonged sample storage.

Should parents have these opportunities? Or am I just exhibiting Big Brother paranoia? MT

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