## Part Seven CONCLUSIONS AND RECOMMENDATIONS

# 1 CONCLUSIONS

## 1.1 Genetic testing context in New Zealand

It is not surprising that New Zealand's primary health-care practitioners (and other non-geneticists) feel unprepared to deal with the existing requests and expected increased demand for genetic testing given the absence of a national policy or strategy for genetics services delivery, or any guidelines for referral for testing or follow-up post testing. Genetics services in New Zealand appear to suffer from a lack of co-ordination and resourcing. Such disorder cannot facilitate the necessary education and guidance required by GPs, paediatricians and other health professionals.

It is vital that GPs and other health professionals know more about genetic testing and genetics services in New Zealand, so that they can better facilitate informed consent; recognise and acknowledge any limitations in their expertise, particularly as they will influence their patients when they discuss testing possibilities;[1] know when to refer patients for genetic testing; and offer some degree of genetic counselling, if required.

Additionally, there is some concern that, as genetic testing becomes increasingly ubiquitous in New Zealand, and is increasingly dealt with by primary health-care professionals, genetic counselling will be inadequate or non-existent (because of training, time and resource deficits).

## 1.2 Does genetic testing of minors raise different issues from those involved in other medical decision-making contexts?

The issue of genetic testing of minors is far from uncontroversial. Genetic testing of minors does raise new issues from those involved in other medical decision-making contexts. Most of the concerns relevant to minors in particular are prompted by the familial and predictive aspects of genetic information. Genetic testing may have far greater personal implications for other family members than decisions made in other medical contexts. Additionally genetic information has the power to be more predictive of future health than other medical tests or interventions, which has implications for the minor's best interests and autonomy. The limited ability of genetic information to predict outcomes is also a source of concern: genetic information can be difficult to understand and its implications easily misunderstood.

## 1.3 Professional guidelines and position papers in respect of genetic testing of minors

### *1.3.1 Minors who cannot give informed consent*

The position statements and guidelines reviewed earlier, and those reviewed by Borry et al., take a generally prohibitive stance towards genetic testing of minors (who cannot give their own informed consent) for untreatable late-onset disorders. Medical benefits comprise the main justification recognised for any genetic testing of children, although special circumstances in which testing may result in other greater psycho-social benefits (as opposed to harms) are considered. There is some ambiguity about the approach to be taken to parental requests for genetic testing for early onset conditions for which no prevention or treatment is available. There appears to be less consensus and certainly fewer recommendations in respect of carrier testing of minors. Those that exist appear to take a slightly more lenient view of such testing than they do of predictive testing for untreatable late-onset disorders.

### *1.3.2 Competent minors*

The HGSA Guidelines on *Predictive Testing in Children and Adolescents* would allow competent minors in New Zealand to give informed consent to predictive genetic testing. Given that there is no professional guidance in respect of carrier testing in New Zealand, presumably the same principles as those espoused in the HGSA guidelines on *Predictive Testing* would apply.

Many of the other prominent position statements and guidelines from professional groups in other jurisdictions also provide that minors can make their own decisions about genetic testing provided that they meet varying standards of competence, understanding and voluntariness. Arbitrary age restrictions are rarely set down.

### *1.3.3 Attitudes and professional practice relating to genetic testing of minors*

The evidence and issues outlined earlier raise significant concerns for the appropriate handling of genetic testing requests for minors, whether on behalf of those who cannot give a valid consent, or by competent minors themselves.

The lack of knowledge amongst New Zealand GPs of genetics and of avenues for seeking further advice on genetic testing obviously has implications for the appropriateness of the ordering of genetic tests, and for informed consent processes.[2] The NHC report strongly emphasised the need for GPs to discuss with or refer most genetic testing (particularly predictive and susceptibility testing) to a genetics service, because of their lack of experience and specialist knowledge of genetic testing. This is particularly important in the case of genetic testing requests for minors, given the special care required during the informed consent process.

The results of the research undertaken with New Zealand GPs are of particular concern in light of the international evidence revealing greater willingness on the part of primary-care health-care professionals to provide predictive genetic tests and carrier tests for minors. Without further investigation and evidence it is difficult to gauge whether our primary health care professionals would be equally enthusiastic about genetic testing of minors. However, there is evidence that GPs are more likely to emphasise the benefits of susceptibility testing for BRCA mutations than the possible psychological harms.[3] There is also evidence that New Zealand's GPs are generally positive about getting involved in genetic testing decisions, if they are well-resourced to do so.

More positively, the GPs surveyed appear to recognise their own limitations in terms of understanding clinical genetics, and currently seem to be more likely to refer patients to a genetics services than order genetic tests themselves.

It is vital that GPs and other health professionals know more about genetic testing and genetics services in New Zealand so that they can better facilitate informed consent; they recognise and acknowledge any limitations in their expertise, particularly as they will influence their patients when they discuss testing possibilities; they know when to refer patients for genetic testing; and they can offer some degree of genetic counselling, if required.

A lack of genetic expertise and genetic counselling is also of concern for competent minors seeking genetic tests because one of the important benefits of genetic testing upon a minor's request is the chance for interaction with a knowledgeable health professional, rather than having to rely upon genetic information given by family members.

Whilst there is some professional guidance on genetic testing of minors from the HGSA, and laboratory protocols on predictive testing generally, these do not appear to be well-publicised or formalised. Pathologists involved in genetic testing would be aware of the HGSA guidance on genetic testing of minors and their oversight of genetic testing requests provides a useful filter for weeding out inappropriate testing of minors (and others); however the *ad hoc* basis upon which it is currently organised does not promote accountability. The lack of a more formal structure and process for genetic testing requests also means that GPs and other health professionals may be making inappropriate requests for testing that are (rightly) not actioned by pathologists, resulting in a waste of time and resources, and increased expectations and stress for at-risk families and children.

## 1.4 Benefits and harms involved in genetic testing of minors

### *1.4.1 Competent minors*

Empirical evidence of benefits and harms of genetic testing is very limited. However, the most recent and extensive evidence points towards testing having the potential to be more beneficial than harmful for competent minors who request testing.

For some of the purported benefits and harms there is no evidence, or only inadequate evidence. Other purported harms do not sufficiently justify a conclusion against genetic testing of competent minors upon request, because they relate equally to other health-care contexts; they relate to adults also; or they can be mitigated or resolved via alternative methods to blanket prohibition.

Many of the potential harms should not be an issue if correct procedures are adhered to, particularly around clear procedures and timeframes for counselling and testing; and clear rules and procedures for method, timing and persons to whom disclosure of results will be made.

Some of the benefits of genetic testing are knowable *a priori*, and at the time of writing there appears to be more convincing evidence for the *benefits* that arise from genetic testing than harms, particularly for competent minors. Evidence of harms is limited and harms specifically or more particularly related to competent minors are even more speculative. Additionally, some of the harms projected as a result of genetic testing can already be seen in minors living at-risk for a heritable genetic mutation.

There is a great need for thorough genetic counselling before a decision is made about whether to undergo genetic testing. The benefits and harms of testing frequently appear dependent on the individual's life story and relationships prior to testing; and plans and level of support after testing (particularly where other harms relating to information management have been appropriately managed). Evidence from predictive testing for HD in adults shows that predictors of negative psychological effects post-testing included negative feelings in the pre-test period.[4]

> *…the issue is complex and troubling. It illustrates the importance of considering each patient as an individual, with particular needs, values and objectives: that a decision to administer or nor to administer the procedure must be determined on a case by case basis, and not as result of predetermined values, objectives, and policy.*[5]

Given the absence of convincing evidence that genetic testing is too harmful for minors generally, competent minors should not be denied the opportunity to undergo genetic testing at their request:

*Although acknowledging that empirical research can have an important role in developing policy guidelines and in affecting ethical decision-making processes, we stress that the results from empirical research alone cannot determine what is good or bad, right, or wrong. ... Ethically salient issues, such as maintaining the child's right for autonomy, confidentiality, and privacy, must be primarily considered when developing formal guidelines.*[6]

### *1.4.2 Minors lacking understanding to give their own consent*

The same limited body of evidence exists against which to judge both the effects of genetic testing of minors who can give their own consent, and testing of those who cannot. However, two very different conclusions have been reached, because of the different consequences of testing each group.

Testing upon a competent minor's request may be beneficial and even enhance that minor's competence and autonomy. However, when testing a child who cannot give informed consent is not clinically indicated there is reason to suspect that psychological or social harms may arise; whether from early knowledge that one will inherit an untreatable disorder; because one has had no say in whether or not to be tested; because parents may treat their child differently, to the child's detriment; or because of an inability to prevent parental dissemination of one's genetic information. Genetic testing for non-medical reasons, as a rule, should not be performed on minors who cannot give their own informed consent to testing because of the lack of evidence of the effects of genetic testing of minors; the fact that many adults choose not to discover their own genetic risk status; and the threats to a child's autonomy and confidentiality. Where there are no medical benefits to genetic testing, such testing should be delayed until the minor can give his or her own consent to testing.

Predictive genetic testing for an early onset condition for which no beneficial medical interventions exist raises fewer concerns than testing for a similar late-onset condition. The same potential benefits exist, but not the same harms – because the danger to the minor's future autonomy, to make a decision and potentially exercise the right not to know the information, is not as salient. Thus, the putative benefits of such testing (relieving anxiety, preparing for onset etc.) may be weighted more heavily in this context regardless of whether or not the disorder is treatable.

However, given that there are no clinical benefits to such testing, and that there may be some harms (changed parental expectations and treatment of child etc.) parental requests for such testing should still be treated very cautiously.

## 1.5 Legal frameworks for medical decision-making – issues raised by genetic testing

### *1.5.1 Minors who cannot give a valid consent*

In determining whether a child not able to understand the nature of genetic testing should be tested the legal test should focus on the benefit(s) that will accrue to the particular child from the testing. Genetic testing of young children who cannot give their own legally effective informed consent should only be carried out where it will prevent onset, alleviate symptoms or provide a cure. This rules out carrier and predictive testing for conditions which do not manifest themselves in childhood and conditions for which there is no medical treatment available.

### *1.5.2 Competent minors*

Self-referral for genetic testing by minors does occur, albeit rarely. The two major objections to permitting minors to consent to genetic testing are that genetic testing is too harmful for minors; and genetic testing, and its implications, are so complex that minors could not be competent to give valid informed consent to testing.

There is no explicit regulation or policy relating to genetic testing of minors in New Zealand. In our view competent minors can consent and also refuse consent to all kinds of genetic testing, pursuant to section 36(1) of the Care of Children Act 2004 (if they are of or over the age of sixteen years), *Gillick* as applied in New Zealand, the Code of Health and Disability Services Consumers' Rights 1996, The United Nations Convention on the Rights of the Child and the New Zealand Bill of Rights Act 1990 also support this view.

Once a minor is deemed competent (statutorily, or in light of her maturity and understanding) then harms and benefits become largely irrelevant (except to the extent that any health professional can refuse to provide services that have no medical benefit), and competent minors' requests for testing should be treated in the same manner as requests by adults. However, if the reference to benefit in section 36(1) of the COCA 2004 is taken to mean that sixteen and seventeen-year-old minors can only consent to procedures that are intended to benefit them, they can still consent to genetic testing, whether or not treatment is available for the disorder for which they are seeking treatment, because there are benefits in knowing one's future genetic health status.

At the time of writing there appears to be more convincing evidence for the *benefits* that arise from genetic testing (some of which are knowable *a priori*), than the purported harms, in respect of competent minors who request genetic testing.

There is a distinct paucity of evidence of actual harm arising from genetic testing of minors, and harms specifically related to competent minors are even more speculative. Additionally, some of the projected harms can already be seen in minors living 'at risk' for a heritable genetic mutation: harm can arise from not acceding to a competent minor's request for genetic testing.

Thorough genetic counselling, and an *individual* assessment of the minor's competence to consent is vital before a minor makes a decision about whether to undergo predictive genetic testing or carrier testing. The benefits and harms of testing frequently appear to be dependent on the individual's life story and relationships prior to testing; and plans and level of support available after testing.

Some have argued that consenting to genetic testing requires a higher degree of competence than consent to other kinds of medical procedures, because of the ethical, psychological and social issues. However, genetic testing raises the same issues in terms of legal competence to give informed consent, as other medical procedures: consent must be given voluntarily, on an informed basis, by a competent person.

Genetic information may be more complex, and contain more uncertainties or probabilities than other medical information. However, this provides a challenge for health professionals to fulfil their obligations under the Code and give competent minors the requisite information in such a way that they can understand it and give legally effective informed consent. There is evidence that adequately educated and informed minors can understand the necessary genetic information to give informed consent to genetic testing.

The legal criteria for assessing competence remain the same in the context of genetic testing: the person must understand the purpose of the procedure, the nature of the procedure and the consequences and implications. Notably, professional position statements on genetic testing of minors do not appear to imply that there are different criteria for assessing competence for purposes of genetic testing.

Larcher's model for assessing competence, coupled with Binedell's questions to consider when exploring whether minors understand the purpose, nature and consequences and implications of genetic testing, may provide appropriate tools with which genetic counsellors (and others) can assess the competence of minors to give legally effective informed consent in the clinical genetics setting.

> *In conclusion, the issue is complex and troubling. It illustrates the importance of considering each patient as an individual, with particular needs, values and objectives: that a decision to administer or not to administer the procedure must be determined on a case by case basis, and not as result of predetermined values, objectives, and policy.*[7]

## 1.6 Disclosure, confidentiality and privacy

### *1.6.1 Disclosure of genetic risk to the minor*

Parents may be under a moral duty to inform their children of heritable genetic mutations when: their children are adults; there is no likelihood of serious harm or risk to life or, notwithstanding, there are no useful interventions available; or when the condition is late onset. However there do not appear to be any legally recognisable duties requiring this type of disclosure (except where it is necessary to prevent permanent injury to the health of or to save the life of a minor under the age of sixteen years, section 152 Crimes Act 1961).

The available evidence suggests that people tend to be in favour of informing their children of their genetic risks, and of informing them themselves, rather than via a health professional. It is, however, obviously a delicate and often difficult task, and the ages vary at which parents consider disclosure appropriate.

Health professionals generally cannot inform a minor about a heritable genetic condition in the family without the permission of the person from whom the health information was gleaned (particularly without an explicit request for the information from an at-risk minor). And yet parents are under no legal duty to inform their children of heritable genetic condition within their families for which they may be at risk.

Whatever parents and guardians decide about informing their children of their genetic risks, the matter is currently unregulated. Parents can be advised by a health professional about an appropriate age and way in which to inform their children but families will make these decisions for themselves.

### *1.6.2 Disclosure of genetic test result to the minor*

Health professionals can encourage parents to inform their children of their genetic test result, and where they refuse to do so health professionals will be subject to fewer constraints in informing the minor themselves (compared to those outlined earlier in respect of informing minors of increased risk based solely on familial genetic information).

A minor who is seeking access to genetic test results, rather than information about risk status on the basis of other family members' health information, does not provoke the same the concerns for a health professional in respect of the privacy and confidentiality of others. However, as with disclosing familial genetic risk, there currently exists *no legal duty to warn* a minor regarding genetic test results.

Minors might be refused access to their genetic tests results pursuant to sections 29(1)(c) and 29(1)(d) of the Privacy Act 1993 if the information were considered prejudicial to their interests, or physical or mental health. Given the complexities, deciding whether or not to disclose a minor's genetic test result will require a very careful case-by-case approach. Genetic counselling will be necessary if minors are to be told that they carry a genetic mutation, and may be necessary regardless of the test result. If minors are aware that they have been tested for a heritable genetic mutation but are denied access to the test results both by their parents and health professionals (who all presumably know the results), one can only guess the psychological harm that could ensue. The concerns raised by disclosing the information, coupled with the concerns raised by refusing to disclose the information, support the argument that carrier or predictive genetic testing that is not clinically indicated should generally be restricted to those who competently request it, and generally not be permitted on the basis of parental consent alone.

Parents do not appear to be legally obliged to inform their children of their own genetic test results: they are not covered by the Privacy Act 1993 or the HIPC or bound by any duties under the Crimes Act to inform their children of genetic test results, except where these may seriously threaten their health or lives (section 152, Crimes Act 1961).

### *1.6.3 Should there be a duty to disclose genetic risks to minors?*

Public health and policy considerations might favour some form of duty to inform children of the existence of their own genetic test results over a duty to inform children about their genetic origins. In regard to genetic test results, the information to be disclosed belongs solely to the child tested: it does not concern the identification of someone else who may not want to be identified, as may information about genetic origins. Additionally, in many cases the genetic test result information will have been identified as having potentially health or life-threatening consequences if undisclosed.

A register should be established to facilitate disclosure to persons who have reached the age of sixteen or eighteen (or earlier if they are competent and personally seek access to the information) of the fact that they underwent genetic testing as children. The information initially disclosed may inform the minor either that the minor underwent predictive or carrier testing as a child, or that some information is available about genetic risk status (if disclosing the fact of having been tested is considered to be too much unsought information for the first contact).

This notification could be achieved in a similar fashion as for relatives who were notified about genetic testing for a familial disorder by the South Australian Familial Cancer Service (FCS).

We consider a genetic test results register established for this purpose to be the appropriate approach to ensuring that people who undergo testing as children are informed of the fact, because:

- It would encourage parents and health professionals to disclose test results to children – as the fact of testing will be disclosed to them anyway;
- It gives the person tested as a child the choice whether or not to learn the information (assuming that he or she has not already been told); and
- It avoids the difficulties of imposing a new duty which may have unwieldy and undesirable consequences in terms of monitoring, enforcement and sanctions.

Genetic counselling services would be required to assist any minors contacted through this process in deciding whether or not to access their test result, and to support them whatever their choice.

And, of course, the privacy of any such register and the information it contained would have to be strictly maintained.

We do not argue that a similar register be established to keep track of information about minors who are simply at increased risk for a heritable disorder but who have not been tested themselves. The issue of disclosure of familial genetic risk cannot be resolved as neatly because it relates to all family relationships, and not just those between parents and their children. The implications are much wider than can be considered here. However, it is desirable that families do inform their children of familial genetic risks and let them make up their own minds about how to use the information (if genetic testing is not clinically indicated during childhood); health professionals should encourage parents to do this.

#### *1.6.4 Should there be legal restrictions to prohibit parents from disclosing their children's health information?*

As with imposing a duty on parents to disclose genetic test results to minors, we are concerned about the enforceability, monitoring and any punitive mechanisms attached to such a duty. However, a duty of confidentiality may be more readily enforced than a duty to disclose information *to* minors: the agency charged with enforcing the duty can take a reactive role once unwarranted disclosure has been made, rather than the more proactive and interventionist role required in order to police disclosure to the minor.

The child's privacy interests need to be weighed against the interests served by allowing parents to disclose their child's genetic test results to certain people or agencies (e.g. school or caregivers so that they can be alert for early symptoms) and the parents' rights to freedom of expression (section 14, New Zealand Bill of Rights Act 1990).

The lack of a parental duty of confidentiality and the difficulties raised by the imposition of such a duty provide another strong argument against genetic testing of children upon the basis of parental consent.

A general rule against genetic testing of children coupled with rigorous genetic counselling emphasising the need to inform the child of the genetic test result, and the need to keep the information private, may be the most effective way to safeguard the child's overall interests: rather than permitting testing and trying to police the sequelae.

### *1.6.5 Competent minors and privacy*

Competent minors who have had genetic testing on the basis of their own informed consent are entitled to the same rigorous protection of their privacy and confidentially as are adults. This is particularly important in the genetic testing context because of the greater family interest in learning the information, and the current lack of any legal duty on parents or others who learn of their results to keep such information private.

## 2 COMPETENT MINORS REQUESTING GENETIC TESTS – IMPLICATIONS FOR PROVIDERS

Where does the above assessment leave the health professional faced with a minor requesting a genetic test?

Health professionals can act upon the informed consent of a minor aged sixteen or over in the same way that they would act upon an adult's request.

Genetic counselling would be required before any predictive testing was undertaken, and presumably also before a minor underwent carrier testing. The competence of a minor under the age of sixteen to make the decision should be assessed during the course of genetic counselling, and the request respected if the minor is competent to make the decision.

But what about when various parties to the decision disagree about testing? Consent issues with respect to competent minors are intricately connected with the issue of health professionals' safety and liability in terms of acting on informed consent. Whether or not a minor's consent or refusal is adhered to often seems to turn upon who agrees or disagrees with the decision made. In New Zealand, as in the United Kingdom, cases where a minor (and/or her parents) *refuse* treatment that health professionals think is in the minor's best interests seem to be the most controversial and litigious.

It is instructive to re-examine the possible scenarios.

- A minor might seek genetic testing with the support of her parents or legal guardians.

When a minor under the age of sixteen is seeking a procedure or treatment with the support of parents or legal guardians, health professionals should nonetheless encourage the exercise of autonomy by helping the minor to participate in or make the decision, giving the minor the opportunity to take responsibility for health decisions.[8] Participating in decision-making, and making decisions, enhances a minor's confidence, autonomy and decision-making abilities.

However, minors should not be forced to take responsibility for the decision, when they do not want to. It will be up to the minor and family to decide upon the final arbiter, and to establish who will give legally effective consent to the testing. Where the minor is competent to give consent the health professional can safely rely upon the informed consent of the minor or guardians.

However, during counselling it must be recognised that 'a child may not be able to exercise free choice in the face of strong parental opinions or parental discord'.[9] Health professionals must be alert to the possibility that a minor has been coerced or subdued into accepting the parents' wishes, and is unaware of the decision-making process. The possibility of the minor being able to make the decision should be raised where a minor 'appears to exhibit a level of maturity that warrants inquiry'.[10]

- A minor might seek genetic testing alone, or with a friend or an adult who is not entitled to give proxy consent to medical procedures on the minor's behalf. The minor's parents or guardians might be unaware or disinterested that their child is seeking genetic testing.

The HGSA policy on *Presymptomatic and Predictive Testing of Children* recommends that discussion between parents and children be encouraged when assessing the competence of a minor.

Given the familial nature of genetic information, and the potentially serious consequences of undergoing a predictive genetic test in particular, the family context is always important when assessing minors' requests for testing. The minor's reasons for seeking a genetic test alone will need to be thoroughly explored. For example, a minor might be seeking a genetic test alone after discovering a 25 per cent risk for the HD mutation, because of a maternal family history, with the mother refusing to discover her own risk status. If the minor tests positive for the HD mutation, her mother will develop HD. The HGSA general policy on *Presymptomatic and Predictive Testing for Genetic Disorders* states that, although this type of issue should not override an individual's access to testing, it should be considered and discussed

in pre-test counselling. The policy recommends involving the parent at 50 per cent risk in counselling, where possible, and discussing whether and how other family members should be approached after test results are known.

Where parents do not know that a young person has sought medical advice, and the young person does not want the parents involved, then the health professional can be in a difficult position. There are very limited exceptions as to when a health professional may imperil the doctor–patient relationship and breach confidentiality. Most of these exceptions revolve around safety, whether of the patient or others. Thus if a health professional did not have any reason to suspect that the young person or others were in danger, by the retention of confidentiality, he or she could generally not discuss the matter with the young person's parents (see discussion on privacy earlier). However, where safe and reasonable, health professionals should encourage young people to discuss their health concerns with a parent or guardian.

It has been argued that

> *Parents are perhaps the most obvious people to provide support when their children undergo predictive genetic testing. It is also possible that this need for parental involvement and support may not be a conscious or explicit desire of young people, but it is nonetheless crucial.*[11]

Thus health professionals should attempt to convince the minor to communicate with the parents or guardians or other supportive adults about the decision. The evidence discussed earlier shows that there are potential harms involved in genetic testing, whether the results are mutation positive or mutation negative, and the young person will need a support system in place during and after the testing process.

- A minor might seek genetic testing against the wishes of her parents or guardian.

  > *The key to managing this situation will be providing the child/young person and their parents with sufficient opportunity to work their differences through, separately or together, depending on the circumstances of the case. The health service involved may be able to assist by providing social work, counselling or cultural support and assistance to family members. In some situations it may be advisable to seek an independent 'advocate' to represent the views and/or interests of the child/young person. … Only when matters cannot be resolved informally should it be necessary to seek legal advice.*[12]

When a minor is of or over the age of sixteen then his or her consent or refusal to consent must be respected. When a minor is *Gillick* competent then his or her consent or refusal to consent should also be respected:

*Where a child's wishes are in conflict with those of a parent (or parents), then great care must be exercised in determining the level of the child's comprehension of the situation and options, and his/her capacity to make reasoned choices ... If the child is judged to be competent, then his or her choice should be respected. (Right 7 of the Code of Health and Disability Services Consumers' Rights.)*

*It is tempting to give a young person's views more weight when these differ from those of his or her parents, because such independence of views suggests that the young person is more likely to be autonomous. However the strength of this conclusion will depend very much on the particular nature of the family relationships.*[13]

What about a case where a health professional is reluctant to act upon a competent minor's consent alone, when a minor is under sixteen and the parents are against the genetic testing? Wertz, Fanos and Reilly argue that testing should be postponed 'until majority, on the grounds that the parents may be aware that the minor is not sufficiently mature'.[14] However in cases of conflict it is important for the professional to determine why parties disagree about testing. Given the familial nature of genetic information, it is important to establish that the parents are not simply against their child being tested because the results may reveal unwanted information about other family members.

Pursuant to section 27 of the COCA 2004 a young person who wanted a carrier or predictive test to which the parents refused to consent could apply to the Court (or have someone else apply on the young person's behalf) for some other person (presumably a person who supported the testing) to be appointed as guardian for the purposes of making medical decisions.[15]

The Court may appoint a person as a guardian of a minor, either in addition to any other guardian or as sole guardian, on application by **any person** or by its own initiative, for a specific purpose or generally, and for a specified time or not (section 27). A Court-appointed guardian would generally have all of the rights and responsibilities of a standard guardian, including the right to consent or refuse to consent to medical treatment on behalf of the minor. Indeed, as the Court has the power to appoint a guardian for a specific purpose and for a specific time, the guardian might be appointed for just such a purpose.

Alternatively, the young person could apply to be placed under the guardianship of the Court (pursuant to sections 31 and 34 of the COCA 2004). Presumably a minor would only be advised to seek to be placed under the guardianship of the Court if there were a reasonable probability that the Court would agree with the minor's view on having a genetic test.

An eligible person (a category which includes a range of relatives, the minor herself and any other person granted leave by the Court) may apply to the Court, pursuant to section 31, for an order placing a minor (who is not married, in a civil union or in a de facto relationship) under the Court's guardianship.[16] Such applications, when granted,[17] give the Court guardianship rights and powers.[18] The Court would thus be the minor's guardian for the purposes of giving consent or refusal to consent to medical procedures or treatment. When the Court is a guardian of a minor its guardianship rights surpass those of any other person.[19]

A young person could also seek to invoke the (High) Court's inherent protective *parens patriae* jurisdiction[20] and be made a ward of the Court in that manner.

If another guardian were appointed by the Court, and gave consent to a genetic test being performed on a minor, the health professional could then be satisfied that she or he was proceeding on the basis of the legally effective consent of the minor's guardian (if he or she had previously been reluctant to act on the consent of the minor alone). However, we reiterate that if a minor under the age of sixteen is competent then a health professional can test on the basis of that minor's legally effective consent.

- A minor might be refusing genetic testing that the parents or guardians want the minor to undergo.

A competent minor's refusal to have a carrier test or a predictive test which is not clinically indicated must always be respected. There would be no clinical harm for the competent minor in respecting the refusal to consent to such a test. Given the controversy over predictive or carrier testing of minors, it is unlikely that a health professional would accept a parent's consent to testing over a competent minor's refusal.

A competent minor who is refusing genetic testing that is clinically indicated (for example, for the FAP mutation) should also have her refusal to consent to testing respected, as an adult's refusal would be.

### 2.1 Conflict with the health professional

We have discussed the options and actions available where a minor and parents disagree as to whether the minor should undergo a genetic test. Minors and/or their parents may also disagree with health professionals about whether a minor should have a genetic test.

A health professional may not want to provide genetic testing when it is not clinically indicated, believing that testing would not be in the minor's best interests.

Disagreements between minors and/or parents and health professionals:

> *may be the result of failures of communication or understanding, rather than basic disagreement about what is best in the situation. It is of course paramount that professionals make every effort to avoid and remedy any miscommunication or misunderstanding. (Right 5 of the Code of Health and Disability Services Consumers' Rights.) Important as it is, good communication will not resolve all conflicts, as there can still be irresolvable differences between reasonable persons about issues involving judgements of benefits, values and probabilities.*[21]

It is important that health professionals seek to understand why a minor and/or parent disagrees with his or her advice about whether or not to undergo genetic testing. This will (hopefully) usually be canvassed thoroughly in genetic counselling. However, as the NZPS report notes, there may simply be irresolvable differences about the value of genetic testing for the particular minor.

There is a concern that when a seemingly *Gillick* competent minor disagrees with a health professional's medical advice the minor will *ipso facto* be considered incompetent. As discussed earlier, in the section on 'Concerns with criteria for competence', this would be an injustice as the wisdom of a decision or its congruence with medical opinion is not a criterion for judging competence in adults.

> *Rejection of professionally recommended treatment by a child under 16 should not automatically be taken as evidence of lack of competence to decide their own health-care. The more serious the consequences of rejecting the treatment, the greater care must be taken in ascertaining the level of understanding and decision-making competence of the child.*[22]

The NZPS discussion document on *Disagreements Between Professionals and Families About Health-care for Children and Young Persons* states that:

> *Where a child or young person is competent to make decisions about his or her own health-care, then such decisions should be respected, as for any adult, whether or not they conflict with professional recommendations. … It should not be assumed that a decision is not well considered and competent just because it is contrary to the best professional judgement.*[23]

However, ultimately, health professionals cannot be forced to act against their clinical judgment (*In Re J (A minor) wardship: medical treatment* [1992] 4 All ER 614), so when a young person (or any individual) is seeking treatment that a health professional considers unwise the minor may be referred elsewhere. In this regard, right 6(3)(c) of the Code states that every consumer has the right to honest and accurate answers to questions relating to services, including questions about how to obtain an opinion from another provider.

It has been argued that health practitioners could be held liable in negligence if they failed to test a competent minor upon request and the minor subsequently bore a child affected with the disorder for which she had wanted to be tested.[24] Putting aside any difficulties in proving the casual nexus, and that the child would not have been born if the competent minor had been tested as requested, New Zealand health professionals cannot be proceeded against for compensatory damages because of New Zealand's accident compensation scheme. They can be sued for exemplary damages; however, the plaintiff needs to prove that the health professional displayed 'truly outrageous conduct which cannot be adequately punished in any other way'.[25] This threshold is unlikely to be met by a health professional who refuses to test a competent minor for carrier status or for a late-onset disorder, given that the predominant discourse suggests that minors should not be tested.

## 3 REGULATORY OPTIONS

Models and analyses of genetic testing have mostly been published in other countries; New Zealand needs to formally examine social and ethical issues of genetics and genetic testing within the New Zealand context.[26]

The concerns raised by practice and attitudes towards genetic testing of minors, the lack of knowledge of many health-care professionals about genetics (and consequently some of the ethical, social and legal implications of genetic testing of minors) and the intricacies of the national genetics services context indicate that New Zealand-specific guidance is required in respect of requests for genetic testing of minors in various scenarios. What form should this guidance take and how directive should it be?

### 3.1 Status quo

#### *3.1.1 Current medico-legal framework*

Essentially the current legal context permits parents to consent to medical procedures and treatments on behalf of their children. If there is some dispute and proceedings are taken under the COCA 2004 or the Children, Young Persons and Their Families Act 1989, or any other proceedings are taken relating to the guardianship or care of the child, the welfare and best interests of the child are paramount. Best interests are to be interpreted widely.

The current legal framework for medical decision-making in respect of incompetent children will not necessarily afford children the protection required in the context of predictive and carrier testing. Currently parents can consent to this kind of testing on behalf of their children, if they can find a health professional to perform the testing. We recommend that a 'substituted judgement' test which emphasises benefit for the child is a more appropriate approach then the 'best interests' approach which allows

factors extraneous to the child to be taken into account. We believe that genetic testing of young children should only be carried out when it will prevent onset, alleviate symptoms or provide a cure. It should not be carried out for conditions which do not manifest themselves in childhood and conditions for which there is no medical treatment available.

The current legal framework is largely appropriate as it pertains to competent minors and medical decision-making: the same general approach should govern requests by competent minors for genetic testing. However, the scope and the nuances of the existing framework may need to be clarified for health professionals to avoid as far as possible the danger that they will be practising defensively and paternalistically in respect of genetic testing requests from competent minors rather than with the more appropriate rights-based focus.

As GIG argues:

> *Whereas GIG totally agrees that every situation should be treated individually, we still believe that there are basic principles which can and should be adhered to. … Being aware of the different procedures and protocols followed by different genetics centres and other units involved in genetic testing, GIG is also concerned that if there are not generally applicable rules and procedures, people may have to shop around, their access to services dependent on the views of individual clinicians.*[27]

The limited variety of genetic testing services in New Zealand makes the ability to shop around for a clinician who will provide services even more difficult. Such shopping around is not possible within New Zealand.

### *3.1.2 HGSA Guidelines*

The HGSA Guidelines are not legally binding but they do give clinicians pause to consider and guidance on the ethical and social issues raised by genetic testing of minors. The Guidelines do of course hold some professional sway, and health professionals who act against the Guidelines must be prepared to justify the breach if required.

The HGSA Guidelines do not only apply to geneticists; they apply to anyone working in the field of genetics. They are thus equally applicable to GPs and other primary and secondary health-care practitioners who come into contact with genetic medicine.

However, the HGSA Guidelines do not appear to enjoy a high profile outside of the clinical genetics and pathology context.

Additionally, there are no HGSA guidelines on carrier testing of minors. Presumably, in practice, the same rationale and principles as those in the HGSA predictive testing

guidelines would be applied: general caution against testing of minors who cannot give informed consent where there is no medical benefit (which will most often be the case in the context of carrier testing), and permitting competent minors to consent to carrier testing.

We do not advocate a blanket prohibition on testing. There are always exceptional cases where discretion is needed. For example, whilst testing under eighteen-year-olds for HD is very strictly advised against, there may be an argument for such testing when a thirteen or fourteen-year-old girl is pregnant and she is at 50 per cent risk of developing HD. She should have the option to be tested for HD in order to decide whether she wants prenatal diagnosis for HD.

#### *3.1.3 Laboratory protocols*

Pathologists' oversight of genetic testing requests provides a useful filter for weeding out inappropriate testing of minors (and others); however the *ad hoc* basis upon which it is currently organised does not promote accountability. The lack of a more formal structure and process for genetic testing requests also means that GPs and other health professionals may be making inappropriate requests for testing that are (rightly) not actioned by pathologists, resulting in a waste of time and resources, and increased expectations and stress for at-risk families and children.

### 3.2 Legislation

Legislation, whether by way of statute or regulation, would be an unusual approach to genetic testing of minors. Although there may be others, Norway is the only country, that we have discovered, which explicitly legislates against genetic testing of minors under the age of sixteen for non-medical reasons. We do not advocate a blanket legislative prohibition on genetic testing of minors. We do advocate that the best interests test be replaced by a substituted judgment test when decisions are made about children who lack the understanding to make the decision themselves.

Public health regulation requiring genetic counselling for predictive genetic testing is appropriate.[28] Parents who request predictive testing of their children should undergo mandatory genetic counselling as to the implications. Compulsory genetic counselling of minors under the age of sixteen seeking genetic testing is justified because minors comprise a more vulnerable group and they would also require a competence assessment which could be undertaken within the genetic counselling session(s). A genetic counselling requirement could be incorporated into the Code of Health and Disability Services Consumers' Rights (e.g. see right 7(6) which requires written consent for participation in research or experimental procedures).

### 3.3 Education

One of the greatest needs in this area is for more education among primary health-care professionals and specialists about genetics and the ethical issues involved, including the existing HGSA Guidelines. Otherwise, there is a risk that they might be referring pre-symptomatic children for genetic tests without the health-care professionals themselves or the families and children being adequately aware of the implications and risks involved. (As mentioned earlier, inappropriate requests for genetic tests may get picked up by the pathologists. However, inappropriate ordering of genetic tests wastes time and resources and may increase stress and engender unrealistic expectations.)

The 1995 Report *Priorities for Genetic Services in New Zealand* considered public education and continuing education of health professionals to be a high priority. The report recommended resourcing of a readily accessible central facility to supply both scientific and lay information nationwide, and the offering of seminars and educational updates to health professionals and support groups by genetics services staff. They also recommended continuing the process of updating factsheets.[29]

The NHC also recommended, in the 2003 Report *Molecular Genetic Testing in New Zealand*, that GPs, specialists and medical students have increased access to genetic education (which would apparently feed into any review of the medical curricula), and that 'ways of making information about genetics more accessible to the public be investigated, including information about the limitations of genetic testing', particularly in relation to predictive testing. They suggested that the public needed access to sources of information other than through medical practitioners. This is a prudent recommendation given the influence that medical practitioners' attitudes may have on their patients.[30]

A new Primary Care Genetics Society has recently been established in the United Kingdom:

> *… to support primary care professionals (PCPs) as they find themselves dealing with an ever demanding public who are continually being fed information about genetics from various sources including the internet and lay media. … and to support and facilitate the educational needs of PCPs to help translate the continuing advances in clinical genetics into practice.*[31]

The Primary Care Genetics Society is partnered with the Genetic Interests Group and other community interest and support organisations. This is a model that may prove useful for educating and supporting New Zealand primary-care practitioners and patients in issues relating to genetic testing.

However, while increased education is certainly desirable, on its own it will not necessarily result in consistency and transparency of decision-making in this area.

### 3.4 National guidelines or code of practice regarding genetic testing for all health professionals

Since as early as 1995[32] there have been concerns raised about the management and structure of genetic services in New Zealand. The 1995 report *Priorities for Genetic Services in New Zealand* recommended that clinical genetic services be nationally co-ordinated and regionally provided. The authors recommended a structure of expert centres with outreach provision to smaller centres.[33] They further recommended that co-ordination of access to genetic tests be through a geneticist or other tertiary specialist, to help ensure that test results were interpreted appropriately. (This recommendation was echoed in the 2003 Report *Molecular Genetic Testing in New Zealand.*) The authors endorsed the option of self-referral or enquiries or referral via a special disease association, particularly for cases where referral had been refused by health-care professionals.[34]

While not all advice on genetic issues needed to come from a clinical geneticist, there needed to be good linkages between genetics services and primary, secondary, tertiary and laboratory services 'to ensure that individuals receive accurate information and appropriate advice'.[35] The Report also suggested that guidelines for referral to genetic services were essential to make the greatest use of a scarce resource.

Regardless of whether the MOH implemented a nationally co-ordinated genetics services programme, the NHC noted in its 2003 Report (*Molecular Genetic Testing in New Zealand*) that protocols were urgently required to assist practitioners to assess when and how different genetic tests should be used. The NHC recommended:

- *Protocols be developed for each test approved for use and, distinguishing between diagnostic, carrier, and prediction or predisposition testing, include:*
  - *consent protocols*
  - *when and how each test should be used*
  - *which practitioner has access to which genetic test based on education and training*
  - ***the appropriateness of the use of each test for children** [emphasis author's own]*
  - *sensitivity to cultural issues and in particular, to the needs and expectations of Māori as tangata whenua*
  - *appropriate levels of support in decision-making for those whose decision-making may be compromised such as those with sensory or intellectual disabilities.*

- *A process be devised for the development of such protocols including involvement from medical geneticists, other health professionals, consumer groups, and disabled people's organisations.*

The NHC contended that:

> *Protocol development would address the inappropriate ordering of genetic tests and lack of confidence of primary healthcare practitioners to provide adequate information and to know when to refer. The committee would favour this approach over regulation.*

The GPs involved in the surveys undertaken by the NHC group and Cameron et al. indicated that they wanted and needed more information about genetic conditions and genetic testing, by way of information sheets, or guidelines for referral for testing and managing mutation-positive patients etc.

New Zealand needs consistent national policy for all health professionals who might come into contact with a request for genetic testing of a minor. GPs, paediatricians and other specialists may be involved with genetic testing without much knowledge of genetics or guidance from HGSA. The guidance on genetic testing of minors, whatever form it takes, needs to be widely disseminated to all registered health professionals and laboratories who might be faced with a request for genetic testing of a minor.

Some feel genetic testing should be handled by genetic specialists with GPs in a backup role, while others feel that GPs are in an ideal position to provide services, with adequate training and support.[36] General Practitioners may know individual families and minors better than specialists: this could have advantages (related to knowledge of family history, issues and dynamics) and disadvantages (potentially reduced clinical objectivity). Regardless, all health professionals faced with genetic testing issues need to be aware of the ethical, legal and social implications raised, and have access to a readily available source of comprehensive and reliable information and guidance. Information from and about genetics services does not currently appear to be readily available to professionals or the wider community.[37]

## 4 RECOMMENDATIONS

- Consistent national policy or guidelines are required for all health professionals who might come into contact with a request for genetic testing of a minor. The national policy or strategy and guidance should come from the MOH – perhaps from a special group established for this purpose. Consultation must be undertaken with the relevant health professionals (particularly clinical geneticists, paediatricians and GPs), to assess the types of roles each group is interested in and capable of fulfilling, and what would be required for each group. Consultation with special interest groups, such as the New Zealand Organisation for Rare Disorders, will also be necessary. Input from the Office of the Children's Commissioner should be involved to ensure that the children's rights and interests are represented.
- The guidance on genetic testing of minors, whatever form it takes, needs to be widely disseminated to all registered health professionals and laboratories dealing with families and hereditary disorders.
- The HGSA should consider drafting guidelines in respect of carrier testing of minors, or attach a protocol to the predictive testing policy stating that it applies to carrier testing, with the necessary amendments in terminology.
- The following suggestions propose issues to be discussed and debated, and possibly included in any guidelines or code of practice:
    - All requests for genetic testing of minors (other than diagnostic or where there is a clear medical benefit to predictive testing) should go through genetics services.
    - Mandatory genetic counselling of parents who make such requests, including discussion about privacy concerns (accords with HGSA recommendations).
    - Mandatory genetic counselling of minors who request predictive or carrier testing. Minors under the age of sixteen need to have their competence assessed anyway, so this can be undertaken within the genetic counselling context.
    - Clear statement of the law regarding the ability of competent minors to give informed consent, outlining, for example, the applicability of *Gillick* competence; the presumption of competence in the Code of Health and Disability Services Consumers' Rights; and article 12 of the United Nations Convention on the Rights of the Child.
    - Professional guidelines and practice in relation to competent minors' requests for genetic tests should focus on assessing competence, and not merely on cataloguing and gauging potential harms.

- Statement that genetic testing decisions do not *per se* require a different standard or method of measuring competence than other treatments and procedures; guidelines for assessing competence generally, based on Larcher's model (as these seem to be somewhat lacking in the more general medical context); and suggestions in respect of assessing competence for genetic testing decisions in particular (based on Binedell's model). Could include referral to a child psychologist or psychiatrist who has some experience in health or genetic counselling where competence is an issue.
- Consent to predictive genetic testing or carrier testing should be in writing: the competent minor's consent (and the parents if they agree, so all parties take ownership of the decision); or the parents' consent on behalf of a younger child. (This requirement could be incorporated into right 7(6) of the Code which states that, where informed consent to a health-care procedure is required, it must be in writing if (a) The consumer is to participate in any research; (b) The procedure is experimental; (c) The consumer will be under general anaesthetic; or (d) There is a significant risk of adverse effects on the consumer.)
- As stated earlier, some of the harms that are caused for competent minors (and also adults) by genetic testing can be mitigated or resolved through appropriate testing and counselling procedures: clear procedures and timeframes for counselling and testing; and clear rules and procedures for method, timing and persons to whom disclosure of results will be made. A waiting period cannot be avoided, given the time that the testing process takes. Interim anxiety or stress could be managed by: foreknowledge of the timeframes involved in the testing process; preparation for the waiting period; and a genetic counselling session scheduled for the waiting period if desired or necessary.
- Similarly, the amount of genetic counselling provided, whether it be too much or too little, is an issue frequently raised by those who have undergone genetic testing. Dissatisfaction with the amount of genetic counselling available is another issue that may equally affect adults. There may be more satisfaction with the genetic counselling process if the entire process, the timeframe and the rationale for each counselling session are clearly explained to each person at the outset. There may be room to add sessions where necessary or desirable. Consumers should be told whether more or fewer counselling sessions are available upon request, or where to go, what to do and whom to talk to if more counselling is required. There may also be leeway to reduce the frequency or length of sessions; although this may be less feasible because the level or amount of counselling needs to keep pace with professionally determined minimum requirements in order to obtain truly informed consent.

- Establishment of a register of genetic test results for persons tested as children on the basis of parental consent.

Recommendations for further research:

– Frequency of current genetic testing and test requests in New Zealand, and what GPs and specialists see as the best way of being informed about the genetic services, information and protocols etc. available.
– Māori, Pacific Island and other ethnicities' views in respect of genetic testing of children, given that other cultures do not necessarily place the same priority on individual autonomy as do Pākehā.

## ENDNOTES

1 See Linda D. Cameron, Jeanne Reeve, Anne Readings, and Ingrid Winship (2002) 'Attitudes about genetic testing for breast cancer susceptibility: A survey of general practitioners, medical students, and women in the northern region of New Zealand' *NZFP* Vol 29, Number 4, Aug 2002, 234-239, 235.
2 National Health Committee (2003) *Molecular Genetic Testing in New Zealand*, p 21.
3 See Linda D. Cameron, Jeanne Reeve, Anne Readings, and Ingrid Winship (2002) 'Attitudes about genetic testing for breast cancer susceptibility: A survey of general practitioners, medical students, and women in the northern region of New Zealand' *NZFP* Vol 29, Number 4, Aug 2002, 234-239.
4 Rony Duncan 'Holding Your Breath, Predictive Genetic Testing in Young People' Ph.D Thesis, Department of Paediatrics and Public Health, University of Melbourne, July 2005, p 63, (available at: http://eprints.infodiv.unimelb.edu.au/archive/00001621/01/PhD_Thesis_Rony_Emily_Duncan_2005_eprints.pdf) referring to Tibben A., Duivenvoorden H.J., Vegter-van der Vlis M., et al. (1993) 'Presymptomatic DNA Testing for Huntington Disease: Identifying the Need for Psychological Inmtervention' *Am J Med Genet* 1993; 48:137-144.
5 N.F. Sharpe (1993) 'Letter to the Editor: Presymptomatic Testing for Huntington Disease: Is There a Duty to Test Those Under the Age of Eighteen Years?' *American Journal of Medical Genetics* 46:250-253, 251.
6 Pascal Borry, Jean-Pierre Fryns, Paul Schotsmans, and Kris Dierickx (2006) 'Carrier testing in minors: a systematic review of guidelines and position papers' *European Journal of Human Genetics* 14, 133-138, 137.
7 N.F. Sharpe (1993) 'Letter to the Editor: Presymptomatic Testing for Huntington Disease: Is There a Duty to Test Those Under the Age of Eighteen Years?' *American Journal of Medical Genetics* 46:250-253, 251.
8 Kathryn McLean (2000) 'Children and Competence to Consent: *Gillick* Guiding Medical Treatment in New Zealand' *Victoria University of Wellington Law Review* 31, 551, 566.
9 Human Genetics Society of Australasia Policy *Predictive Testing in Children and Adolescents*, Version 2, April 2005, p 4, accessed on 8 May 2006 from http://hgsa.com.au/images/UserFiles/Attachments/Predictivetesting(General)APRIL2005.pdf.
10 Kathryn McLean (2000) 'Children and Competence to Consent: *Gillick* Guiding Medical Treatment in New Zealand' *Victoria University of Wellington Law Review* 31, 551, 573.
11 Rony Duncan 'Holding Your Breath, Predictive Genetic Testing in Young People' Ph.D Thesis, Department of Paediatrics and Public Health, University of Melbourne, July 2005 (available at: http://eprints.infodiv.unimelb.edu.au/archive/00001621/01/PhD_Thesis_Rony_Emily_Duncan_2005_eprints.pdf).
12 Ministry of Health (1998) *Consent in Child and Youth Health*, Wellington, p 13 (available at: http://www.moh.govt.nz/moh.nsf/0/0E1E14F99334EBBACC256C150002EFEC.)

13 *Disagreements Between Professionals and Families about Health-care for Children and Young Persons*, A discussion document prepared for the Paediatric Society of New Zealand and the Board of Paediatrics and Child Health of the Royal Australasian College of Physicians, August, 2001, available at www.paediatrics.org.nz/PSNZold/disputes_01.html#1, accessed 21/06/06.

14 Dorothy C. Wertz, Joanna H. Fanos, and Philip R. Reilly, (1994) 'Genetic Testing for Children and Adolescents. Who Decides?' *JAMA* 272: 875-81, 880.

15 It is noted that s 46 of the Care of Children Act 2004 allows children of or over the age of 16 years to apply to a Family Court Judge to have a parent or guardian's decision or refusal to give consent reviewed. However, this provision is of limited assistance to young people of or over the age of 16 years in the medical-decision making context because pursuant to s 36 they have the capacity to give their own consents or refusals to consent. However, it could potentially be relevant if it was contended, in accordance with s 36(5), that another's consent was sufficient or necessary for medical treatment pursuant to another enactment or rule of law, despite a minor being of or over the age of 16 years. A 16 or 17 year old could use s 46 to have the Court review consent or refusal to consent decisions in that context. However, given the clear (and recent) parliamentary intention to give 16 and 17 year old minor's the right to consent and refuse to consent as if they were of full age, it would be very difficult to argue that a guardian's opposing decision could take precedence.

16 And/or an order appointing a person as the agent of the Court either generally or for any particular purpose.

17 Between the making of the application and its disposal the child becomes subject to the Court's protection (s 34(1)(a), see Dick Webb et al. *Butterworths Family Law in New Zealand*, Eleventh Edition, Vol 1, Butterworths, Wellington, 2003, 6.302). However, the child does not become subject to the guardianship of the Court until the order is made – see Dick Webb et al *Butterworths Family Law in New Zealand*, Eleventh Edition, Vol 1, Butterworths, Wellington, 2003, 6.302, which cites *W v Director-General of Social Welfare and others* [1990] NZFLR 353.

18 Pursuant to s 34 the Court then has the same rights and powers in respect of the person and property of the child as the High Court had in relation to wards of the Court immediately before the commencement, on 1 January 1970, of the Guardianship Act 1968. Except that the Court may not: direct any child who is of or over the age of 16 years to live with any person unless the circumstances are exceptional; or commit for contempt of Court a child or the child's spouse for marrying without the Court's consent while the child is under the guardianship of the Court (s 34 (2)).

19 See Dick Webb et al *Butterworths Family Law in New Zealand*, Eleventh Edition, Vol 1, Butterworths, Wellington, 2003, 6.302.

20 *Parens patriae* is an ancient prerogative jurisdiction of the Crown that goes back to the 13th century. Under the jurisdiction the Crown had all the power and duty to protect the persons and property of those unable to look after themselves. The jurisdiction was conferred by the Crown on the Courts and applies in New Zealand pursuant to s 16 of the Judicature Act 1908: Peter Spiller, *Butterworths New Zealand Law Dictionary* (Fourth Ed), Butterworths, Wellington, 1995. Its existence was further reinforced in *Pallin v Department of Social Welfare* [1983] NZLR, 266, 272, per Cooke, J: 'I think too that a High Court Judge has a residual jurisdiction, derived from the right and duty of the Crown as parens patriae to take care of those who are not able to take care of themselves, to give a consent on behalf of a child for the purposes of s 32: compare Re L (An Infant) [1968] P 119. This power would be sparingly exercised, especially by way of overriding a refusal of consent by a parent, guardian or guardian *ad litem*. But I would hold that it does exist in New Zealand …'

21 *Disagreements Between Professionals and Families about Health-care for Children and Young Persons*, A discussion document prepared for the Paediatric Society of New Zealand and the Board of Paediatrics and Child Health of the Royal Australasian College of Physicians, August, 2001, available at www.paediatrics.org.nz/PSNZold/disputes_04.html#1, accessed 21/06/06.

22 *Disagreements Between Professionals and Families about Health-care for Children and Young Persons*, A discussion document prepared for the Paediatric Society of New Zealand and the Board of Paediatrics and Child Health of the Royal Australasian College of Physicians, August, 2001, available at www.paediatrics.org.nz/PSNZold/disputes_03.html#1, accessed 21/06/06.
23 *Disagreements Between Professionals and Families about Health-care for Children and Young Persons*, A discussion document prepared for the Paediatric Society of New Zealand and the Board of Paediatrics and Child Health of the Royal Australasian College of Physicians, August, 2001, available at www.paediatrics.org.nz/PSNZold/disputes_03.html#1, accessed 21/06/06.
24 Donna L. Dickenson (1999) 'Can children and young people consent to be tested doe adult onset genetic disorders?' *BMJ* 318: 1063-1065, 1063.
25 *A v Bottrill* (New Zealand) [2002] UKPC, 44, 9 July 2002, per Lord Nicholls of Birkenhead, para 44.
26 World Health Organisation, Genomic Research Centre, *Case Study: New Zealand*, accessed 21 December 2006 from www.who.int/genomics/policy/newzealand/en/.
27 *GIG Response to the Clinical Genetics Society Report: The Genetic Testing of Children* (1995), p 2, accessed 13 February 2007 from www.gig.org.uk/docs/gig_testingchildren.pdf.
28 Dorothy C. Wertz and Philip R. Reilly (1997) 'Laboratory Policies and Practices for the Genetic Testing of Children: A Survey of the Helix Network,' *American Journal of Human Genetics*, volume 61, 1163–1168, 1166.
29 *Priorities for Genetic Services in New Zealand*, A Report to the National Advisory Committee on Core Health and Disability Support Services by Dr J.W. Dixon, Dr I. Winship, and Dr D.R. Webster, 1995, pp 17-18.
30 Linda D. Cameron, Jeanne Reeve, Anne Readings, and Ingrid Winship (2002) 'Attitudes about genetic testing for breast cancer susceptibility: A survey of general practitioners, medical students, and women in the northern region of New Zealand' *NZFP* Vol 29, Number 4, Aug 2002, 234-239.
31 See http://www.pcgs.org.uk/default.asp for more information, accessed 4 April 2007.
32 The first major report on New Zealand's genetics services was released in 1995 – *Priorities for Genetic Services in New Zealand*, A Report to the National Advisory Committee on Core Health and Disability Support Services by Dr J.W. Dixon, Dr I. Winship, and Dr D.R. Webster, 1995.
33 *Priorities for Genetic Services in New Zealand*, A Report to the National Advisory Committee on Core Health and Disability Support Services by Dr J.W. Dixon, Dr I. Winship, and Dr D.R. Webster, 1995, p 7.
34 *Priorities for Genetic Services in New Zealand*, A Report to the National Advisory Committee on Core Health and Disability Support Services by Dr J.W. Dixon, Dr I. Winship, and Dr D.R. Webster, 1995, p 17.
35 National Health Committee, Fifth Annual Report (December 1996), accessed 27 January 2007 from www.nhc.govt.nz/publications/annual5/genetic.html.
36 Sonya White, Deborah McLeod (2003) *Genetic Testing: A survey of New Zealand General Practitioners' knowledge and current practice, Prepared for the National Health Committee*, pp 4 and 33, accessed from www.nhc.govt.nz/publications/Genetics/GeneticTestingFinalReport.pdf on 27 January 2007.
37 There should be an option for self-referral to genetics services. Competent minors, in particular, may be able to use this avenue for exploring their options if they were refused access to predictive or carrier testing by a primary-health professional.