Part One INTRODUCTION

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… we can learn from their experiences, but decisions made in other countries will not necessarily suit our needs. New Zealanders need to make their own choices.[1]

In New Zealand parents have the legal right to seek and make decisions about medical treatment and interventions on behalf of their children. Such is part of the bundle of rights and responsibilities that come with guardianship. Parents exercise authority over a child's medical treatment until the child is competent enough to make such decisions in or his or her own right.

This report looks at whether genetic testing of children raises new issues that require a different paradigm in terms of medical decision-making for children. Does genetic testing raise new issues or concerns that are not effectively addressed under existing frameworks? Who should decide whether a child undergoes a genetic test: a child; a parent; a health professional; the State? If minors generally do not make medical decisions on their own behalf, at what age are or should they be recognised as competent to do so? At what age should they be recognised as competent to consent to or refuse to consent to a genetic test?

This analysis regarding regulation of genetic testing of minors rests upon the premise that there is a need to respect the autonomy of minors, no matter what their age. This premise results in two different arguments. First, that competent minors should be genetically tested upon their own request or informed consent, in deference to their autonomy. Secondly, that minors too young to make their own decisions should not be genetically tested, in deference to their future autonomy.

The underlying principle of respect for autonomy means that the limited evidence regarding benefits and harms also favours genetic testing of competent minors upon request or their own informed consent; adults may seek and consent to genetic testing, despite the limited evidence about the effects. Notwithstanding, the evidence of benefits and harms of genetic testing of competent minors is equivocal at best, and arguably appears to support the view that more benefits than harms may arise from such testing.

The principle of respect for autonomy requires us to be more cautious in respect of younger children where there is only limited evidence regarding benefits and harms. Where the outcomes of imposed testing are unknown and may include some harm, then there is even greater reason, in terms of their future autonomy, for younger children to make their own decision about testing and for it to be respected. The need to respect their autonomy overrides any parental rights or family concerns which may prompt a request for genetic testing, unless very serious harm will come to the child as a result of not acceding to parental wishes in respect of testing.

Respect for autonomy is the fundamental principle upon which this analysis is based because, regardless of moral or ethical premises, the law protects individual rights to self-determination.

We conclude that predictive or carrier testing of children who cannot give their own informed consent is to be discouraged, primarily because it infringes the child's autonomy, and also because of the lack of evidence about whether such testing is beneficial or harmful. However, we do not suggest that such testing should be legislated against, as has been done in Norway. There needs to be room for some discretion for those situations in which the child will be better off being tested than not, limited as those circumstances might be. It is not the State's place to make these decisions instead of parents and health professionals.

We conclude that our existing medico-legal framework allows competent minors to give their own informed consent to genetic testing. However, we suggest that New Zealand-specific professional guidelines on genetic testing of minors, reinforcing the legal capacity of competent minors, would better protect their position, whilst also raising awareness of the ethical, legal and social implications of genetic testing amongst a wider circle of health professionals, rather than just clinical geneticists.

1 WHAT IS A CHILD OR MINOR?

While there are common notions[2] of what a 'child' is there have been various conceptions regarding to whom the terms 'minor' or 'child' apply across history, disciplines and jurisdictions. The definition or categorisation often turns upon the purposes for which it is sought.

The most important meanings of the terms 'child' and 'minor' for the purposes of this part of the report are the legal definitions. There is no single overriding definition of 'child' for the purposes of all New Zealand law,[3] and children are given various rights, responsibilities and protections at divergent ages.[4] It can thus be difficult to categorically state who is legally a 'child' in New Zealand. The definition very much depends on the context.[5] Such variations can be confusing but also beneficial, by reflecting children's increasing competency as they develop. Provisions requiring that children be dealt with in accordance with their age and maturity also recognise the fact that individual children mature at different times.

The most relevant definitions of 'child' for the purposes of this section of the report are contained within the Care of Children Act (COCA) 2004 and the United Nations Convention on the Rights of the Child (UNCROC).

Note that while both instruments set an arbitrary age limit in terms what age group is covered by the term 'child', they both also give significant recognition to the evolving capacities of children, and the need to involve children of all ages (where possible) in decisions affecting them.

The COCA 2004 defines a child as 'a person under the age of 18 years'. The duties, powers, rights and responsibilities of guardianship terminate when the child turns eighteen; the child marries or enters into a civil union; the child lives with another person as a de facto partner; or it is ordered by the Court (section 28, COCA 2004).

Pursuant to article 1 of UNCROC a child means 'every human being below the age of eighteen years unless, under the law applicable to the child, majority is attained earlier.'

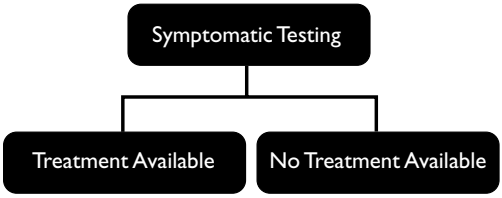
Thus, for the purposes of this section of the report, the terms 'child' and 'minor' refer to children under the age of eighteen years. We in no way mean to diminish persons under the age of eighteen by referring to them by the somewhat archaic word 'minor' – we merely use the expression as the most appropriate term in the legal context at this time, and to avoid any confusion caused by using the word 'child' (which can of course also refer to *adult* children).

2 WHAT IS GENETIC TESTING?

The same genetic tests that can be carried out on adults to identify gene variants or genetic mutations can also be carried out on minors.

2.1 Symptomatic testing

Figure 1: *Symptomatic testing*



Symptomatic testing is undertaken as part of routine medical care when a minor presents with symptoms of a disorder that may have a genetic basis. For example, testing for fragile X is part of a routine medical work-up for a child with developmental and speech delay.[6] For some conditions such as cystic fibrosis there may be interventions available that can alleviate some of the symptoms of the disorder. For others, such as Batten's disease (a fatal neurodegenerative disorder characterised by mental impairment and progressive loss of sight and motor skills), little can be done to halt the symptoms and progress of the disorder.[7]

2.2 Predictive testing

Predictive testing can be presymptomatic i.e. for conditions with 100 per cent penetrance (such as Huntington disease), or probabilistic[8] i.e. indicating susceptibility to a condition (e.g. BRCA 1 and BRCA 2 mutations and breast and ovarian cancer). Most predictive tests are for susceptibility.

Both presymptomatic and susceptibility tests can be carried out for early-onset conditions, which usually manifest in childhood or adolescence (e.g. retinoblastoma and Familial Adenomatous Polyposis),[9] or late-onset conditions, which manifest later in life (e.g. Huntington disease).[10]

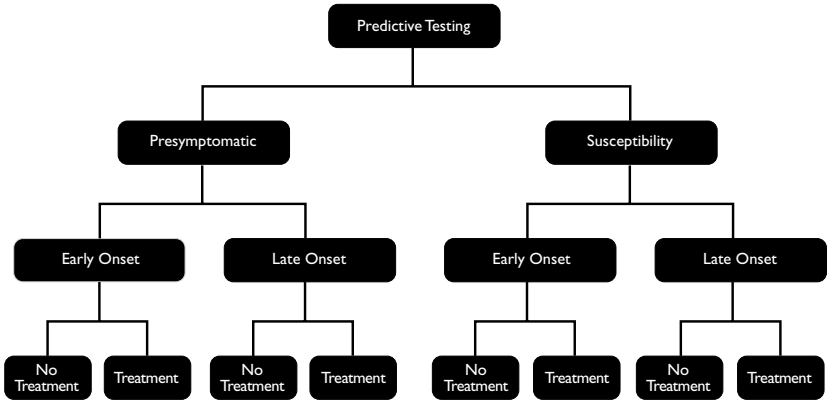
For some heritable genetic disorders there may be medical interventions available to prevent or delay the onset of the condition or to effectively manage or minimise the symptoms ('treatment'). For others (e.g. most neurodegenerative disorders) there is often no effective medical prophylaxis or treatment available ('no treatment').

When a genetic mutation is not fully penetrant, and thus only indicates varying degrees of susceptibility to a disorder, the risk of developing the associated disorder varies according to a number of factors. These include the particular gene(s) or genetic variation(s) in question; the total genetic environment;[11] the individual and the lifestyle involved; and environmental factors. A great deal of uncertainty lingers – further factors that might affect a person's likelihood of getting a particular disorder remain unknown.

It is important to note that even when a genetic mutation is presymptomatic or fully penetrant, the genetic test results cannot always predict how severe the manifestation (or the expressivity) of the disorder will be in the particular person tested. That is, it currently can be very difficult to tell how mildly or severely the disorder will present in the person tested.

Additionally, there are no guarantees as to the age of onset of any of these types of conditions. There is still a great deal of residual uncertainty regarding the interpretation of presymptomatic genetic test results.

Figure 2: *Predictive testing*



2.3 Carrier testing

Carrier testing is also available to determine whether a minor carries a recessive autosomal or X-linked genetic mutation, or a major chromosomal mutation, for a condition that he or she may pass on to future offspring. Examples include cystic fibrosis, Tay-Sachs, sickle-cell disease and fragile X syndrome.

There is a difference in implication between carrying an autosomal recessive mutation, and carrying an X-linked mutation. A female carrier of an X–linked mutation has a 50 per cent chance of passing the disorder on to her son, and a 50 per cent chance of passing carrier status on to her daughter. Those who carry an autosomal recessive disorder have, at the most, a 50 per cent chance of passing carrier status on to their children, and a 25 per cent chance of bearing an affected child, only if they procreate with another carrier of the disorder. Otherwise, the risks of passing on carrier status, or the disorder, are often much lower. The degree of risk depends on the risk within the population e.g. cystic fibrosis carriers are more common in Northern European populations than in Asian populations.

Carriers are not always unaffected by the disorder for which they carry the mutation. For example, female carriers of X-linked adrenoleukodystrophy (a fatal neurodegenerative disorder characterised by learning disabilities, seizures, gait, co-ordination difficulties and progressive dementia)[12] can exhibit symptoms of the disorder.[13] Female carriers can also be affected by haemophilia B, Duchenne muscular dystrophy (the most common form of muscular dystrophy in children) and other X-linked disorders.[14]

ENDNOTES

1 Independent Biotechnology Advisory Council (IBAC) (2001) 'Genetic testing, an introduction to the technology that is changing our lives: Some issues to consider', at 2. Available at: www.morst.govt.nz/Documents/publications/researchreports/IBAC-Genetic-Testing.pdf (viewed 30 January 2007).

2 A boy or girl from the time of birth until he or she is an adult; a son or daughter of any age (*Cambridge Advanced Learner's Dictionary*. Available at: http://dictionary.cambridge.org/define.asp?key=13062&dict=CALD (viewed 26 May 2006)); or a young person especially between infancy and youth (*Merriam-Webster Online Dictionary*. Available at: www.m-w.com/dictionary/child (viewed on 26 May 2006)).

3 While s 4 of the Age of Majority Act 1970 states that 'For all the purposes of the law of New Zealand a person shall attain full age on attaining the age of 20 years', the Act does not affect any reference in any enactment or instrument to an age expressed in years. In the absence of a definition or of any indication of a contrary intention, the expressions 'adult', 'full age', 'infant', 'infancy', 'minor', 'minority', 'full capacity', 'majority' and similar expressions in any enactment are to be construed in accordance with twenty being the age of majority. However, as will become apparent in the following discussion, for almost all purposes eighteen years is the true age of majority in New Zealand. Persons of or over the age of eighteen have all the legal rights and responsibilities of adults, with a very small number of exceptions, among the most notable being that: a person must be twenty years of age to gamble in a casino (s 303, Gambling Act 2003); for persons under the age of twenty there is a lower breath and blood alcohol limit when driving (s 11, Land Transport Act 1998); and persons under the age of twenty-five years cannot adopt a child, unless the prospective adoptee is a relative, in which case the adopter must be at least twenty years of age (s 4, Adoption Act 1955). There has been recent debate as to whether the Age of Majority Act should be amended to make the age of majority eighteen years instead. Members of the Youth Parliament 2004 spent quite some time discussing a mock amendment to the Act proposing just such a change, and voted by an overwhelming majority (104 ayes, 14 noes, 2 abstentions) to lower the age. See Fourth Youth Parliament, 2004, Parliamentary Debates, *Hansard*, 16–17 August 2004. Available at: www.clerk.parliament.govt.nz/Content/Hansard/Final/YOUTH_PARLIAMENT_2004.pdf (viewed 26 May 2006). Similarly, the Human Rights Commission's submission for the Discussion Paper *Responsibilities for Children: Especially When Parents Part* opined that an age of majority of twenty 'does not appear to sit comfortably with UNCROC, which defines children as being persons under the age of eighteen. This may result in difficulties in the development of global policies for children. It is notable that New Zealand has previously been criticised by the Committee on the Rights of the Child for having taken a piecemeal approach to the development of policy relating to children, and that the Government has recently undertaken initiatives in this area. Such initiatives may be furthered by bringing the age of majority into line with UNCROC.' Available at: http://66.102.7.104/search?q=cache:PP_J7dgA3s4J:www.hrc.co.nz/index.php?p=13681&id=13690+"Age+of+Majority"+&hl=en&gl=nz&ct=clnk&cd=9 (viewed on 26 May 2006).

4 For information about rights, responsibilities and protections at various ages, see *When Can I?* YouthLaw Tino Rangatiratanga Taitamariki, 2005; Robert Ludbrook *A New Zealand Guide to Children and the Law* (Lower Hutt, New Zealand: Inprint Limited, 1991); *Youth and the Law 2003, A Comprehensive Guide to the Law Relating to Young People from Birth to Adulthood*, third ed., revised and updated by M. Pawson (Wellington, New Zealand: Educational Resources for Legal Resources Trust, 2002).

5 For example, two of the main purposes of the criminal law are to punish offenders and to deter would-be offenders. Thus for the purposes of New Zealand's criminal law a child as young as ten years old can be charged with murder or manslaughter, and prosecuted, and dealt with in a similar fashion to an adult accused. Aside from murder and manslaughter, children cannot be prosecuted in the criminal courts until the age of fourteen years (s 272, Children, Young Persons and

Their Families Act 1989 and ss 20 and 21, Crimes Act 1961). A private member's Bill – the Young Offenders (Serious Crimes) Bill – is currently before Select Committee. The principle behind the Bill, according to the explanatory note, is 'adult punishment' for 'adult crimes'. If passed, the Bill would reduce the age at which young offenders could be prosecuted from to twelve. Conversely, laws relating to the purchase of tobacco products and alcohol are intended to protect children and young people from the harms those products can bring: persons cannot purchase these products until they reach the age of eighteen.

6 McConkie-Rosell A. and Spiridigliozzi G.A. 'Family matters: A conceptual framework for genetic testing in children' in *Journal of Genetic Counseling*, Vol. 13, No. 1, February 2004, 9–29, at 14.

7 Information available at: www.ninds.nih.gov/disorders/batten/batten.htm (viewed 14 February 2007).

8 Throughout the literature the terms predisposition, susceptibility and probabilistic testing are all used to refer to testing for genetic variations that do not have 100 per cent penetrance. I will use them interchangeably.

9 'Mutations in the APC gene predispose the individual to cancer. Colon polyps typically are present by mid teens, with 80-90% of untreated patients developing colon cancer by age 45-50 years (Peterson et al., 1991). Medical guidelines recommend screening for hepatoblastomas from birth to age 5 years and sigmoidoscopy every 1 to 2 years beginning at age 10-12 years (Burt 2000).' McConkie-Rosell A. and Spiridigliozzi G.A. 'Family matters: A conceptual framework for genetic testing in children' in *Journal of Genetic Counseling*, Vol. 13, No. 1, February 2004, 9–29, at 15.

10 'Huntington disease (HD) is a neurodegenerative disease inherited in an autosomal dominant fashion. In adulthood, HD presents with three primary features: involuntary movements (commonly chorea), psychiatric disturbances (personality and behavioural changes) and cognitive impairment). … Huntington disease usually presents in the fourth or fifth decade of life but can occur earlier or later. Juvenile HD is defined by presentation prior to the age of 21 years. Only 0.5–2% of all cases of HD present before the age of 20 years.' Geevasinga N., Richards F.H., Jones K.J. and Ryan M.M. 'Juvenile Huntington disease' in *Journal of Paediatrics and Child Health* 42 (2006) 552–4, at 552 (online version).

11 Mason J.K. and Laurie G.T. *Mason and McCall Smith's Law and Medical Ethics* seventh edn (Oxford: Oxford University Press, 2006) 208.

12 Available at: www.ninds.nih.gov/disorders/adrenoleukodystrophy/adrenoleukodystrophy.htm (viewed 14 February 2007).

13 Shaw-Smith C.J., Lewis S.J. and Reid E. 'X-linked adrenoleukodystrophy presenting as autosomal dominant pure hereditary spastic paraparesis' 75 *Journal of Neurology Neurosurgery and Psychiatry* 686, 2004.

14 Puck J. 'Editorial: X inactivation in females with X-linked disease' *New England Journal of Medicine* Vol. 338: 325–8, 1998.