



Department of Law

**A QUESTION ABOUT THE GENETIC
TESTING OF CHILDREN IN
NEW ZEALAND**

**The limitation of parental authority to
consent on behalf of their child**

Lauren J Lindsay

Thesis submitted for assessment with a view to obtaining the degree of
Master in Comparative, European and International Law (LL.M.) of the
European University Institute

Supervisor: Professor Francesco Francioni

European University Institute



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LIST OF ABBREVIATIONS

COCA	The Care of Children Act 2004 (NZ)
The Code	Code of Health and Disability Services Consumers' Rights Regulation 1996 (NZ)
The CRC	The United Nations Convention on the Rights of the Child 1989
The Charter	The Charter of Fundamental Rights of the European Union 2000
The Child Convention	The United Nations Convention on the Rights of the Child 1989
The ECECR	The European Convention on the Exercise of Children's Rights 1996
The ECHR	The Convention for the Protection of Human Rights and Fundamental Freedoms 1950
The European Convention on Human Rights	
The Genetic Testing Protocol	The Additional Protocol to the Oviedo Convention concerning Genetic Testing for Health Purposes (opened for signature 27 November 2008) (not yet entered into force)
The HADCA	The Health and Disability Commissioner Act 1994
The Health Practitioners Act	Health Practitioners Competence Assurance Act 2003
The HGRP	The Human Genome Research Project
The NZBORA	The New Zealand Bill of Rights Act 1990
The Oviedo Convention	The Convention for the Protection of Human Rights and Dignity of the Human Being with regards to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine
The UDBHR	The Universal Declaration on Bioethics and Human Rights 2005
The UDHGHR	The Universal Declaration on the Human Genome and Human Rights 1997
The UDHR	The Universal Declaration of Human Rights 1948

INTRODUCTION

The participation of children and minors in genetic testing raises issues concerning the limits and extent of parental authority and the rights of children and minors involved. Genetic testing, as a form of health care (be it considered a treatment or a procedure), comes under the umbrella of medical law. Medical law has been described as a "subset of human rights law",¹ a view which is adopted in other scholarship.² In this way, medical law can be informed by (international) human rights law, which prioritises the self-determination and dignity of the patient.³ Underlying self-determination and dignity is autonomy which is a common thread throughout this paper. The concept of choice, present and future, is at the heart of all issues concerning genetic testing. Informed consent is the medical expression of personal autonomy and choice. The issue of consent is particularly thorny with children. One must ask who has the capacity to decide? Who has the right or responsibility to decide? What role do children's rights have to play in health care decision making? Does the type of disease being tested for change the analysis? What are the health practitioner's obligations? Do third parties have the right to know about genetic information gleaned from family members which may impact on them? The questions are many and not exclusively legal. They also demand a consideration of bioethical, medical, social and psychological issues. This paper does not purport to answer all of these questions. Possible answers to many have already been

¹ I Kennedy and A Grubb, *Medical Law* (3rd edn Butterworths, London 2000) 3.

² E Wicks, *Human Rights and Healthcare* (Hart Publishing, Oxford 2007).

³ *Ibid* 2.

furnished in New Zealand within the second volume of the Reports submitted by the Human Genome Research Project ("HGRP").⁴

Indeed, the motivation for this paper arose out of the work that has already been undertaken by the HGRP in New Zealand and stems from one particular suggestion of theirs: that the scope of the power of parental consent to genetic testing of their children should be limited to testing where it is to the child's benefit, rather than in the child's best interests. The recommendation purports to collapse a hitherto multi-faceted best interests approach into a single "benefit" test. As will be discussed, where the parent has the authority to consent, such consent is currently limited to interventions in the child's best interests. The HGRP argues that the best interests standard is too open to manipulation and justifies the taking into account of factors which do not actually pertain to the child's best interests. Moreover, the child's best interests will only be objectively assessed by a court if the court is asked to intervene for a particular reason.

This recommendation was made without any emphasis on international law or the principles that can be gleaned from the jurisprudence of the European Court of Human Rights. This thesis aims to re-examine the issue against this broader international and European background, with an emphasis on the United Nations Convention on the Rights of the Child,⁵ the Convention for the Protection of Human Rights and Fundamental

⁴ Human Genome Research Project, 'Genes, Society and the Future: Volume II: The Genetic Testing of Children' (Dunedin 2007).

⁵ United Nations Convention on the Rights of the Child, opened for signature 20 November 1989, 1577 UNTS 3 (entered into force 2 September 1990) ("The Child Convention" or "The CRC"). --The Child Convention has been ratified by all UN member states (on hundred and ninety three parties) except for Somalia and the United States.

Freedoms,⁶ the Convention for the Protection of Human Rights and Dignity of the Human Being with regards to the Application of Biology and Medicine and its Genetic Testing Protocol⁷ and the fundamental principle of human dignity of the child.

This thesis focuses on the genetic testing of individuals as distinct from the genetic screening of populations. It will not focus on the genetic testing issues relating to pre-implantation genetic diagnosis, prenatal testing (of foetuses or embryos) or newborn screening. Such issues have a tendency to engage a highly charged moral and religious debate which this paper deliberately seeks to avoid.⁸ Similarly, the testing of intellectually disabled children has not been the focus of research but analogues will undoubtedly emerge from this paper's examination of a child *simpliciter's* competence to consent and the legal consequences which pertain thereto.

Certain expressions used herein need to be defined. The expressions child/children, minor and young person/people will be used in this paper to refer to any person under the age of 18, in accordance with the definition contained in the CRC and in the Care of Children Act 2004.⁹ To a lesser extent, this paper will use the expressions newborn, baby and infant to

⁶ Convention for the Protection of Human Rights and Fundamental Freedoms, opened for signature on 4 November 1950 (entered into force 3 November 1953) ETS No. 005 ("The European Convention on Human Rights" or "the ECHR").

⁷ Convention for the Protection of Human Rights and Dignity of the Human Being with regards to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (entered into force 1 December 1999) ETS No. 164 ("The Oviedo Convention"); Additional Protocol to the Convention on Human Rights and Biomedicine concerning Genetic Testing for Health Purposes (opened for signature on 27 November 2008) ETS No. 203 ("Genetic Testing Protocol"). The Genetic Testing Protocol is of particular importance and can perhaps provide some guidance for what is to happen in New Zealand, most importantly in terms of regulatory considerations.

⁸ RC Schwartz, *Heredity and Hope: the Case for Genetic Screening* (Harvard University Press, London 2008) 227.

⁹ Care of Children Act 2004 ("COCA").

describe extremely vulnerable children and the very young; generally speaking a newborn child is between one to four weeks old. Though "infant" is also employed as a legal term equivalent to "minor", this paper has deliberately avoided the use of the term in this manner. To do so would disconnect the expression from society's use of the term; that is, referring to a baby.¹⁰

The expression "health practitioner" is any person who is, or is deemed to be, registered with an authority as a practitioner of a particular health profession.¹¹ At present, the following practices are legally recognised health professions: chiropractic, dietetics, medical radiation technology, medicine, medical laboratory science, nursing, occupational therapy, physiotherapy, podiatry, psychology and psychotherapy.¹² This paper will employ the expressions *health practitioner/professional* to denote any professional registered in New Zealand in compliance with the Health Practitioners Act who is involved in the genetic testing process and thereby owes duties and obligations towards the child patient and/or the child's guardians and/or affected third parties arising out of that genetic test. In practice, the practitioners involved in genetic testing will be the child's doctor (or GP), a specialist clinical geneticist (accessed through clinical genetics services) and the genetic counsellor. The latter need not necessarily be a third party but could also be, for example, the GP fulfilling a counselling role. Clinical genetics is the medical speciality which

¹⁰ As a matter of etymology, "infant" derives from the Latin expression *in fans* meaning unable to speak.

¹¹ Health Practitioners Competence Assurance Act 2003 ("Health Practitioners Act"), s 5(1).

¹² All of these professions are set out in Schedule 2 of the Health Practitioners Act. The latter profession, psychotherapy, was added as a health profession by the Health Practitioners Competence Assurance (Designation of Psychotherapy Services as Health Profession) Order 2007.

"provides a diagnostic service and genetic counselling for individuals and families with, or at risk of, conditions which may have a genetic basis".¹³

Guardian (and guardianship) will be used within the meaning of the definition in s 15 of the COCA to mean that person who has, in relation to the child:

- (a) all duties, powers, rights and responsibilities that a parent of the child has in relation to the upbringing of the child;
- (b) every duty, power, right, and responsibility that is vested in the guardian of a child by any enactment;
- (c) every duty, power, right, and responsibility that, immediately before the commencement, on 1 January 1970, of the Guardianship Act 1968, was vested in a sole guardian of a child by an enactment or rule of law.

In general terms, the expression guardian or parent (deemed to be a guardian pursuant to s 17 of the COCA) is used to refer to that person who has the authority to act on behalf of the child.

My general methodology was to take an international and European perspective on the issue of best interests versus benefit, one which could then be applied to the question in New Zealand. The dignity of the child was employed to anchor the debate and inquire which test, in light of any distinctions, dignity would favour.

No meaningful discussion could ensue without an understanding of genetic testing. The first section therefore begins with an outline of the genetic testing process and highlights the common distinction between symptomatic and pre-symptomatic testing, a particular research preference for pre-symptomatic genetic testing of children being taken in this paper. The crux of the problem was quickly identified to be the interplay between the

¹³ Clinical Genetics Society, 'What is Clinical Genetics' (2009) <http://www.clingensoc.org/info_genetics.htm> accessed 25 February 2009.

child's competence to consent and the role that the child's best interests, as perceived by guardians and courts, would play. This demanded an exposition of the meaning of competence and New Zealand's legal position on children and medical decision making. Section one goes on to discuss theories of competence before describing the current position in New Zealand concerning the distinction between incompetent and competent children and the attendant legal consequences of that distinction in a medical context.

Having laid the domestic legal foundations, an examination was undertaken of the meaning afforded by international law to the expressions at issue in this paper: the principle of best interests and the closely related right of a child to express his or her views; and the term "benefit". Given the subject matter of genetic testing and children, the focus remained on the Child Convention and international instruments related to science and technological advances. This provided a solid theoretical backdrop to the next step: consideration of the application of these principles by a judicial body.

The second section therefore seeks to elucidate the nature of the best interest principle. It will discuss the principle of best interests of the child, its use and application in international law and the closely related principle of the views of the child, as protected under Article 12 of the CRC. How the principle of the best interests of the child set out in Article 3 of the CRC and Article 8 right to family life contained in the European Convention on Human Rights interact in practice will be outlined. As an important regional human rights court, the Strasbourg Court can provide valuable guidance as to how the best interests principle can operate at a level of human rights adjudication.

It was intended to use the Strasbourg Court to also explore how the term benefit is relied on in practice. However, no ECHR jurisprudence was identified regarding the meaning of benefit in the context of child medical decision making. In its place, the decision of the High Court of Australia in *Marion's Case*¹⁴ was selected as providing a suitably authoritative exposition of that question. High Court of Australia decisions are highly persuasive in New Zealand and this case served the dual purpose of drawing on the distinction between best interests and benefit whilst also relying on language of dignity. It is the third section which examines the use of the expression *benefit* in both this decision and in international conventions. It will be argued that there are four material differences between the two tests. For reasons of substance and procedure, this thesis argues that the best interests test remains preferable to that of benefit.

As a final step in this paper's methodology, the differences perceived between best interests and benefit were pitched against the principle of dignity. It was important to develop a general picture of dignity, including its history, its use within the international and New Zealand legal systems before applying it to the question in this paper. Accordingly, the fourth section tests the preliminary conclusions derived in section three against a coherent conception of dignity and concludes that the dignity of the child is more likely to be advanced by a test which possesses the four main features that the benefit test lacks.

¹⁴ *Department of Health & Community Services v JWB & SMB* [1992] HCA 15 (HCA) ("*Marion's Case*").

SECTION ONE: WHAT IS GENETIC TESTING AND THE NEW ZEALAND LEGAL POSITION

PART 1: AN OVERVIEW OF THE GENETIC TESTING PROCESS

I. What is Genetic Testing?

A genetic test involves taking a sample of DNA-containing cells from an individual and then applying scientific techniques to that person's DNA to obtain certain genetic information. The National Health Medical Research Council¹⁵ defines it as a test which "reveals information" which may be performed on DNA, RNA or protein or may involve measurement of a substance that indirectly reflects gene substance.¹⁶

Genetic information stems from and reflects the particular variations in genetic sequence the individual has. Certain genetic sequences almost always cause disease. Others have a less certain effect on health and may create a susceptibility to a condition, or protect the individual from a condition. Then there are those sequences which underlie physical differences such as hair colour and those which have no effect at all.

Genetic testing may be done for medical, non-medical or reproductive purposes. Genetic testing for medical purposes may be defined as "the analysis of the genetic material to identify differences that determine whether an individual has, or will develop, a particular

¹⁵ The National Health and Medical Research Council (NHMRC) is the Australian body which supports health and medical research, and develops and provides health and ethical advice to the community, health professionals and governments concerning health care and medical research. See generally: National Health Medical Research Council, 'NHMRC' (<<http://www.nhmrc.gov.au/index.htm>> accessed 7 September 2009).

¹⁶ National Health Medical Research Council, 'Ethical Aspects of Human Genetic Testing: An Information Paper' (NHMRC, 2000) 9. Haemoglobin (a protein) electrophoresis is carried out to diagnose carriers of beta-thalassaemia. As regards measurement, one can measure blood cholesterol to diagnose familial hypercholesterolemia in a child whose parent has the disorder.

disorder, or has an increased probability of doing so".¹⁷ Genetic disorders may include chromosomal abnormalities, single gene disorders such as cystic fibrosis, familial cancer or cancer prone syndromes such as inherited breast cancer, and birth defects with a genetic component of which cleft lip and palates provide common examples.¹⁸ The testing techniques applied vary in the specificity of their inquiry. At a more general level, the subject's chromosomes are examined under a microscope (used to diagnose "obvious" chromosomal abnormalities such as an extra chromosome or large chromosome breakage). A more specific species of testing involves probing the subject's DNA for particular genetic mutations in known genes.

Genetic testing for non-medical purposes is carried out to "define individuality and to establish relationships by the use of normal genetic variants, or polymorphisms".¹⁹ Testing for the purposes of defining individuality is predominantly employed to establish identity in a forensic setting. Testing to establish relationships is most commonly used to establish parentage under the popular label of "paternity testing". For the avoidance of doubt, this paper is not concerned with the following:

- (a) genetic testing to establish parentage;

¹⁷ Ontario Law Reform Commissioner, 'Report on Genetic Testing' (Toronto 1996) 11.

¹⁸ Clinical Genetics Society, (accessed 25 February 2009) above n 13.

¹⁹ Ontario Law Reform Commissioner, above n 17, 25.

(b) genetic testing in a research context, be it a clinical trial or other medical research or genetic testing for population studies, such as tracing the historical origins of populations;²⁰ or

(c) genetic testing for reproductive purposes (apart from carrier testing). This is most commonly used for couples contemplating having children and wishing to make informed decisions about the health of their future child; couples wishing to employ pre-implantation genetic diagnosis during IVF treatment; and couples wishing to have pre-natal screening.

II. The Conditions Genetic Testing Can Uncover

A genetic sample can contain a vast amount of information about an individual. In terms of genetic diseases, a genetic sample can be taken for predictive or carrier purposes. Predictive testing can be pre-symptomatic or susceptibility-focussed. Pre-symptomatic tests are undertaken to detect conditions which *will* almost certainly develop at some stage during the child's life. For this reason, conditions of this nature are referred to in scientific parlance as having 100 percent penetrance: the possession of a particular gene (genotype) will inevitably manifest itself in the form of the disease (phenotype). The point at which this physical expression occurs is not static. Pre-symptomatic conditions may develop during childhood ("early-onset") or later in life ("adult-onset"). Susceptibility testing is undertaken to detect conditions that *may or may not* develop. The test searches for genetic

²⁰ There is much scholarship on the subject of the ethics of medical research on children, including research involving genetic tests. For more information, refer: M Otlowski, 'Protecting Genetic Privacy in the Research Context: Where to From Here' (2002) 2 Macquarie Law Journal 87; RE Ashcroft and others, 'Children's Consent to Research Participation: Social Context and Personal Experience Invalidate Fixed Cutoff Rules' (2003) 3 The American Journal of Bioethics 16; Karen Eltis, 'Genetic Determinism and Discrimination: A Call to Re-Orient Prevailing Human Rights Discourse to Better Comport with the Public Implications of Individual Genetic Testing' (2007) 35 The Journal of Law, Medicine & Ethics 282.

mutations which are known to carry an increased predisposition towards the development of a particular disease. A positive test for the mutation in question reveals an increased risk of manifesting the disease to which that mutation relates. These diseases can also be divided into "early-onset" and "adult-onset" sub-categories. The most common types of susceptibility testing occur in the realm of familial cancer such as breast and ovarian cancer and the concomitant presence of the BRCA 1 and BRCA 2 mutations. Although a person who tests positive for the BRCA 1 mutation is often referred to as a "carrier" of the gene, this does not retroactively place the testing within the "carrier testing" category. Both kinds of predictive testing enable one to assign a reasonable statistical probability to the likelihood of the subject developing the condition. Yet they offer no insight into the severity of the predicted condition nor the exact age at which it will arise.

Carrier testing is about identifying whether a person is carrying a defective gene which may affect his or her *offspring*, rather than his or her *own* health. However, those who carry a genetic disease and those who suffer its symptoms are not two mutually exclusive groups. For this reason, the distinction between carrier and predictive testing, in principle and practice, is not entirely stable. First, there are situations where a person will be carrying a gene which both affects his or her own health and has implications for the health of any future children. Familial cancer is a good example. Second, carriers are not always unaffected by their condition. Carriers of many X-linked diseases (such as haemophilia and muscular dystrophy) are frequently affected.²¹ In this grey area the distinction between carrier and predictive testing is best framed in terms of a rough test of comparative impact. If the mutated gene may affect the person's own health to a greater or

²¹ HGRP, above n 4, 6.

equivalent degree to that which any potential offspring might experience then we refer to it as "predictive testing". If the mutated gene may affect the individual's children to a greater degree, then it is designated as "carrier testing". It must be conceded that a distinction based on these lines is neither perfect nor logically demanded. Yet it does provide a coherent taxonomy against which this paper's central issues can be examined.

There are two main types of genetic carrier status distinguished according to the type of disorder to which the status relates: *autosomal recessive disorder* on the one hand; and *sex-linked disease or balanced chromosomal translocation* on the other. Carriers of the former can potentially²² transmit that disorder to their offspring only if their respective partners also carry the gene for the same disorder. Carriers of the latter risk transmitting the disease to their offspring regardless of their partners' genetic status.

III. Is Genetic Information Special? The Notion of Genetic Exceptionalism

The genetic information of each person is unique and, like most medical information, highly personal.²³ Yet the breadth and depth of the detail genetic information can reveal sets it apart from the ordinary run of medical information. The idiosyncratic nature of genetic information can²⁴ facilitate the identification of one particular individual to the exclusion of everyone else. It can provide insight into that person's future health and life

²² Generally, if both parents carry the recessive gene, then there is a 25 percent chance that the child will inherit *both* recessive genes, thereby expressing the disorder. This is because each person has two copies of every gene, one inherited from each parent. Each parent has a 50 percent chance of passing on the mutant recessive gene to the child (i.e. one out of two genes). This results in a 25 percent chance of the child carrying both recessive genes.

²³ See *S and Marper v The United Kingdom* (2009) 48 EHRR 50 (ECtHR (Grand Chamber)) at [70]-[77].

²⁴ I use "can" in the sense that to identify that a particular sequence belongs to person X, one must have a sample from X to compare it to.

prospects.²⁵ Once acquired, genetic information has the ability to completely destroy any anonymity the subject hitherto enjoyed. The scope for misuse and the consequences of said misuse are unquantifiable due to considerable uncertainty about the true significance and meaning of genetic information. Uncertainty derives from three related sources. First, the interrelatedness of genetic information to other factors such as the total genetic environment and the physical environment of the individual is deeply obscure. Second, widespread misconceptions as to what it means to be a "carrier" of a predisposing gene. Third, the absence of a limit as to the scientific advances to which genetic information may be subjected to in the future.²⁶ While, as technology currently stands, genetic information is immutable, there is no reason to suppose this will remain so. Our legal analysis must pay particular attention to this heightened level of uncertainty not just in determining what should be done with genetic information but the logically prior, and potentially more important question, of when genetic information in a readily decipherable form should come into existence.

One of the central reasons genetic information is cited as special is its *familial or shared* nature. The individual from whom genetic information is derived is not the only person who may maintain an interest in its contents. Genetic information may tell us something about blood relatives, both succeeding (potential or actual) and preceding generations. If I test positive for familial adenomatous polyposis (an inherited predisposition to bowel polyps which, if left undetected, lead to cancer) it tells me my future child will have a 50 percent chance of developing that disorder. If I turn out to be a carrier of the cystic fibrosis

²⁵ Otłowski, above n 20, 91.

²⁶ *S and Marper v The United Kingdom* above n 23, [71].

gene, it informs me that one of my parents is also a carrier and that my sister could also be a carrier. This dynamic is likely to render issues of disclosure, confidentiality and privacy of particular importance. More relevantly, it inexorably leads to the existence of a range of competing motivations, beyond the medical interests of the tested subject, for conducting a genetic test of an individual.

Plainly, the pervasive reach of genetic information can impact on family dynamics; it may strengthen, weaken, create or remove existing family relationships.²⁷ It may have many psychological manifestations: it may create anxiety amongst the family for the affected person; the affected person may worry about siblings or his/her reproductive future; a sibling who is "cleared" may have feelings of guilt for the sibling who was not. The potential scenarios are as infinite as the reactions and interests of the individuals involved to the genetic information at issue. A particularly uneasy balance may need to be struck between the privacy interests of the person from whom genetic information is derived and the benefit another person may have through the disclosure of a genetic susceptibility.²⁸ The hereditary significance of genetic information renders this balance particularly awkward given that the competing interests will be arising within the same familial or, at least, biological unit.

The current international position is to recognise that the nature of genetic information warrants special protection. This is evidenced through the international instruments which single out genetic information as unique and/or put in place specific standards for the

²⁷ National Health Medical Research Council, 'Ethical Aspects of Human Genetic Testing: An Information Paper' above n 16, 10.

²⁸ Ibid, 10.

management of genetic information.²⁹ Opponents of "genetic exceptionalism" argue that genetic information is just like any other form of personal health information and does not require special protection.³⁰ Indeed, analogies can be drawn between genetic and other medical information. For instance, whether a person is HIV positive is highly personal, sensitive and can have implications for others. Certainly, HIV status and genetic information have considerable analogues. But the conclusion that this symmetry demands neither species of information to be treated exceptionally rests upon a flawed premise. A person's HIV status is not like any other form of personal health information. The positive law of many jurisdictions recognises this.³¹ Just as HIV status engages special considerations, so too does a person's genetic status.

Admittedly, less exceptional non-genetic tests (although ultimately with a genetic basis) can be used to identify predictive information about an individual (blood cholesterol level for example). However, as Otlowski argues, it is the cumulative effect of the various characteristics of genetic information which afford it the status of special information.³² It cannot be seriously argued that one's most recent cholesterol test has the wide ranging implications and engages the broad range of legitimate interests that genetic information of

²⁹ E.g. see Convention on Human Rights and Biomedicine; International Declaration on Human Genetic Data 2003 (Adopted by UNESCO on 16 October 2003); Universal Declaration on the Human Genome and Human Rights 1997 (adopted by UNESCO on 11 November 1997) ("UDHGHR").

³⁰ T Murray, 'Genetic Exceptionalism and 'Future Diaries': Is Genetic Information Different from Other Medical Information?' in M Rothstein (ed) *Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era* (Yale University Press, New Haven 1997).

³¹ In New Zealand, criminal nuisance has been interpreted to criminalise an HIV positive individual having unprotected sex without disclosing his status: *Police v Dalley* [2005] NZAR 682 (DC). See generally, A Evans, 'Critique of the Criminalisation of Sexual HIV Transmission' (2007) 38 VUWLR 517. New Zealand is also considering amendments to the Public Health Act 1956 to permit health authorities to disclose HIV status to at risk individuals.

³² Otlowski, above n 20, 92.

the type already mentioned does. Regardless of the direction in which one's moral stance leads on the "genetic exceptionalism" debate, as we have already seen, the international community has specifically recognised genetic information as special. This alone provides support for treating it differently from other types of medical information.

PART 2: COMPETENCE & CAPACITY - THEORY AND CRITERIA

Given that this paper's central question is engaged upon a child being deemed *incompetent* or *incapable* of consenting, it is necessary to gain an appreciation of what these concepts entail. The expression competence or capacity refers to the ability of a person to provide *legally* binding consent to a particular treatment, procedure or intervention. Beyleveld and Brownsword characterise a person in law who is competent to give consent as being a "subject of consent".³³ Consent operates as a procedural, rather than substantive, justification for a particular action. First, consent is relied on as authorising the action notwithstanding the merits of the action itself. Second, it operates to prevent the consenting person from claiming against the person who did the action that the particular action was wrong.³⁴ Finally, consent is rationalised within the language of wrongs rather than substantive rights.³⁵

It is difficult to identify the exact criteria of competence, as these change depending on the circumstances. However, it is generally agreed that consent is valid if it is freely given and informed. It follows that a person has capacity to consent if two conditions hold. First, the person is capable of forming his or her own judgment and making a decision which is free from the influence of others (freely given consent). Second, the person is able to understand and apply information which is relevant to the decision at hand (informed).³⁶

³³ D Beyleveld and R Brownsword, *Consent in the law* (Hart Publishing, Oxford 2007) 93.

³⁴ *Ibid* 61.

³⁵ Take the example of a medical procedure. It is meaningful to say that consent has operated to preclude the health practitioner from committing a wrong (assault). Yet, we do not speak of consent as justifying a breach of the patient's rights. The difference is more than semantic. The language we use can have a significant effect on the way in which we perceive the doctor-patient dynamic. - -

³⁶ Beyleveld and Brownsword, *Consent in the Law* above n 33, 12-13.

Translating these requirements into Gewirthian-speak, the subject of consent must have the capacity to form a will about the giving or refusing of consent.³⁷ Such capacity must be developed, present at the relevant moment and based on a relevant knowledge and understanding of the nature and significance of the consenting act itself.³⁸

For Raz, the key to competence is a fully autonomous decision, although he somewhat incongruously acknowledges that the fully autonomous person does not exist.³⁹ Autonomy is the condition permitting each individual to determine his life-plan.⁴⁰ An autonomous decision is taken where an individual has identified those desires which are consistent with

³⁷ Ibid 99. Gewirth's moral theory of rights is set out in A Gewirth, *Reason and Morality* (University of Chicago Press, Chicago 1978). Gewirth argued that agents who (prospectively at least) have the capacity freely to select and act for a purpose (with a will), logically accept and are bound by the "Principle of Generic Consistency" (PGC) whereby agents have reciprocal rights and duties to respect one another's freedom and well-being. The PGC is binding on all agents, not because they may take a moral viewpoint of some kind, but simply by virtue of an agent adopting any reason at all to a particular action. To defend this latter claim, Gewirth attempted to show that if an agent were not bound by the PGC, it would contradict its status as an agent. His view requires that rights be understood according to the will theory of rights. In MacCormick's view, this creates problems for theories of children's rights. Because some children have no capacity for forming a will, a will theory cannot explain the undisputed existence of children's rights. For this reason, Gewirth's account cannot provide an exhaustive general theory of rights: N MacCormick, 'Children's rights: a test-case for theories of rights' (1976) 32 *Archiv fur Recht-und Sozialphilosophie* 305. However, MacCormick's approach need not compel the outright rejection of Gewirth's. That a theory has failed to explain entirely does not mean that it has entirely failed to explain. Adoption of the gradualist theory of rights for children which protects both interests and choices provides a coherent account of children's rights consistent with Gewirth's: when children are young, they have rights to protect their interests; and as they get older, gradually their rights evolve to protect their choices: S Brennan, 'Children's Choices or Children's Interests: Which do their Rights Protect?' in D Archard and CM Macleod (eds), *The Moral and Political Status of Children* (Oxford University Press, Oxford 2002). It is clear from both MacCormick's and Brennan's analyses that children do have rights. Gewirth's theory does accommodate children as "potential" agents. Beyleveld and Brownsword expand on this and characterise children as potential ostensible agents whose interests can be protected by a third party, usually the parent: Beyleveld and Brownsword *Consent in the Law*, above n 33, 118.

³⁸ Beyleveld and Brownsword, *Consent in the Law*, above n 33, 99-100.

³⁹ J Raz, *The Morality of Freedom* (Oxford University Press, Oxford 1986) 155, cited by J Eekelaar, 'The Interests of the Child and the Child's Wishes: the Role of Dynamic Self-Determinism' (1994) 8 *International Journal of Law and the Family* 42, 56.

⁴⁰ Eekelaar, above n 39, 50.

his or her goals, achievable within attainable social forms, and decided to pursue them.⁴¹ A decision apparently inconsistent with the individual's self-interest *may* still be autonomous.⁴² This view is consistent with Gewirth's theory of rights: what matters is that a choice is free, not that the choice itself violates the decision maker's perceived interests.

Occasionally, a presumptively competent individual may be stripped of that capacity by virtue of the nature of the action consented to. In these circumstances, the giving of consent satisfying the two above conditions is insufficient to render that action lawful.⁴³ Cases of assisted suicide provide a morally contentious example. A less extreme example appears in *Wackenheim v France*.⁴⁴ There, the Human Rights Committee concluded that a domestic prohibition on the practice of dwarf throwing was justified on the grounds of human dignity notwithstanding the consent of the person being thrown. The Committee upheld the French formulation of dignity which operated as a communitarian constraint on an individual's will.⁴⁵

Eekelaar draws on Raz's work in examining the notion of competence for children. In terms of having a goal which is "achievable within attainable social forms", Eekelaar emphasises that children's goals may be unrealistic and thus constitutive of an incompetent decision. As children do not tend to have a settled identity or life goals any stated goal

⁴¹ Ibid, 55.

⁴² Ibid, 55.

⁴³ Beyleveld and Brownsword *Consent in the Law*, above n 33, 16-17.

⁴⁴ *Wackenheim v France* CCPR/C/75/D/854/1999: France, 26 July 2002 (Human Rights Committee).

⁴⁵ The concept of dignity and its application to the question considered in this paper is discussed in detail in section four.

must be subjected to some scrutiny.⁴⁶ Hence, a child's wish will not be competently expressed if the wish is unrealistic or its realisation extremely improbable.⁴⁷ Yet, one must equally acknowledge that a child's competence should not be denied on the grounds of a presumption that life goals are usually unsettled when developing.⁴⁸ To do so would empty a child's capacity to consent entirely of content. A complex balance must be struck. First, one must consider the nature of the goals themselves. A distinction should be drawn between "incidental" and "important" goals. A child can be held more capable of consenting to the former while the latter may require more time to develop. If, in light of this background, a child's goals are seriously unstable then a conclusion of incompetence is justified.⁴⁹ Second, consideration must also be given to the source of the goal: the child or the parent. Third, and relatedly, a choice needs to be made as to the level of influence that the law will countenance a third person (parent) exerting over a child before a decision is considered invalid for want of free will.⁵⁰

The foregoing analysis suggests that a child will be competent if: s/he is capable of forming her/his own judgment about a particular decision, having considered the information at hand, free from any external influence (in particular parents); and the decision itself is not clearly unrealistic or improbable. The unsettled nature of a child's goals must be borne in mind when establishing whether the decision is really unrealistic or improbable.

Essentially, children need time to make decisions.

⁴⁶ Eekelaar, above n 39, 52.

⁴⁷ Ibid, 55.

⁴⁸ Ibid, 56.

⁴⁹ Ibid, 56.

⁵⁰ Ibid, 56-57.

PART 3: NEW ZEALAND'S APPROACH TO CHILDREN AND CONSENT

I. Statutory Overview

The relevant statutory framework is found in the COCA and the Health And Disability Commissioner Act 1994 ("the HADCA"). The COCA represents, in effect, a comprehensive legislative code regulating the day to day guardianship and care of children in New Zealand. The HADCA establishes the legislative machinery for the promulgation of a document setting out a series of legally enforceable rights for health care consumers which bind both private and public health care providers. These rights are contained within the Code of Health and Disability Services Consumers' Rights Regulations 1996 ("the Code").⁵¹ The HADCA also constitutes a Health and Disabilities Commissioner to investigate and determine complaints relating to purported breaches of such rights.

Regardless of capacity, a child patient is deemed a "health consumer" within the meaning of the HADCA and is thus the bearer of a bundle of rights, as set out in the Code. These rights include the child's right to be treated with respect;⁵² the right to be free from discrimination, coercion, harassment and exploitation;⁵³ the right to have his or her privacy respected;⁵⁴ the right to dignity and independence;⁵⁵ the right to effective

⁵¹ The Code became law on 1 July 1996 as a regulation issued pursuant to the HADCA.

⁵² The Code, Right 1.

⁵³ The Code, Right 2.

⁵⁴ The Code, Right 1(2).

⁵⁵ The Code, Right 3.

communication⁵⁶ and the right to be fully informed in order to make an informed choice or provide informed consent.⁵⁷

The HADCA defines informed consent to a procedure by a consumer as mandating that consent be freely given by the consumer or a person entitled to consent on the consumer's behalf and be obtained in accordance with those requirements prescribed by the Code. The person acting on the child's behalf is entitled to agree to or refuse treatment. Every consumer is presumed competent to make an informed choice and provide informed consent unless there are reasonable grounds for believing otherwise.⁵⁸ It has been suggested that a young child who clearly lacks the maturity and competence to give informed consent is a reasonable ground for rebutting this presumption.⁵⁹ Despite diminished competence (which is not defined by age), a child will retain the rights to effective communication and to information provided in a manner commensurate with that child's ability to understand.⁶⁰

II. The Meaning of Competence

While the HADCA's definition of "informed consent" is clearly predicated on the competence of the consent provider, it is noticeably silent on the requirements of competence. On an operative level, Ministry of Health guidelines issued to practitioners direct that a competent person is able to make "a rational, informed choice about

⁵⁶ The Code, Right 5.

⁵⁷ The Code, Right 6.

⁵⁸ The Code, Right 7(2).

⁵⁹ HGRP, above n 4, 254.

⁶⁰ See Rights 5 and 7(3) of the Code and Ministry of Health (New Zealand), 'Consent in Child and Youth Health: Information for Practitioners' <www.moh.govt.nz> accessed 24 March 2009, 17.

accepting or refusing the treatment or service being offered, or authorising the collection and use of information".⁶¹ The expressions "rational and informed" are capable of capturing the formulations of competence suggested by Raz and Eekelaar as articulated in the preceding part. In positive law terms competence is action-specific. As a matter of principle, a child at a given age may be competent to make some decisions and not others: a 12 year old boy may be able to consent to having his wisdom teeth removed, on the basis that his health practitioner has judged him competent and thus legally able to provide binding consent; that same child may not be deemed competent to consent to a more significant operation, such as the removal of a non-malignant tumour.

From the age of 16, a young person is presumed competent.⁶² For children under the age of 16, New Zealand appears to adopt an understanding-based approach to competence to consent, to the exclusion of the strictly applied status-based test determined, somewhat arbitrarily, according to age.⁶³ This understanding-based approach crystallised in the landmark decision of the House of Lords in *Gillick v West Norfolk and Wisbech Area Health Authority*.⁶⁴ There, the House of Lords held that:⁶⁵

⁶¹ *Ibid*, 3.

⁶² *Hawthorne v Cox* [2008] 1 NZLR 409 (High Court) ("*Hawthorne*"). This presumption is consistent with the "dual focus on determination and assistance in s 16(1)(c)" of the COCA and "the general policy shift towards a more-child-centred approach to guardianship": *Ibid* at [54]. It is also in line with scholars who argue for the adoption of the precautionary principle where consent is concerned: Beyleveld and Brownsword *Consent in the Law*, above n 33, 101. This principle addresses the risk of treating a competent person as incompetent thereby not recognising that person's rights and in practice requires that competence be presumed.

⁶³ Ministry of Health (New Zealand), above n 60, 59.

⁶⁴ *Gillick v West Norfolk and Wisbech Area Health Authority* [1986] 1 AC 112 (HL) ("*Gillick*")

⁶⁵ *Ibid* at 188-189 per Lord Scarman.

the parental right to determine whether or not their minor child below the age of 16 will have medical treatment terminates if and when the child achieves a sufficient understanding and intelligence to enable him or her to understand fully what is proposed. It will be a question of fact whether a child seeking advice has sufficient understanding of what is involved to give a consent valid in law.

Here we see the reappearance of the competence criteria discussed above. Children deemed to have "sufficient understanding and intelligence" are said to be "*Gillick*-competent". *Gillick* is understood as setting the threshold of understanding higher for children compared to adults.⁶⁶ It is the health practitioner (or the courts) who will decide whether or not the child is *Gillick* competent. In *Hawthorne v Cox*, Heath J effectively endorsed the philosophy underpinning the notion of *Gillick* competence in acknowledging the consistency of the COCA with *Gillick*.⁶⁷ In so doing, His Honour, albeit obliquely, settled a significant debate as to the ability of *Gillick* common law principles to coexist alongside the COCA.⁶⁸ Freeman has argued that competence must be understood in terms of "capability of understanding rather than in terms of what the child actually understands" in the sense that a child may not understand what is involved because s/he was not given full information. The HADCA goes some distance towards facilitating understanding by recognising the child's right to effective communication.

⁶⁶ New South Wales Law Reform Commission, 'Young People and Consent to Health Care' (NSW Law Reform Commission, Sydney 2008) 82.

⁶⁷ *Hawthorne*, above n 62.

⁶⁸ In a medical context, s 36 of the COCA permits children aged 16 and over to consent to medical treatment or procedures as if they were adults. The silence of s 36 on the ability of children aged *under* 16 to consent to identical procedures combined with the saving in subsection (5) of rules of law which did not include *Gillick* led some to argue that *Gillick* competence had no place under the COCA. For a summary of the debate see: HGRP, above n 4, 303-306. The HGRP's summary of the applicable law broadly reflects the position underpinning Heath J's analysis in *Hawthorne*.

III. The Legal Significance of Competence

A. The child who lacks competence

The applicable legal landscape pertaining to consent differs according to whether or not the child is competent to provide consent. At both common law and under statute, if a child is considered to lack competence the repository of the power to consent to medical treatment is the child's guardian. Health practitioners who disagree with a guardian's decision regarding treatment (such as a refusal to consent to a life-saving blood transfusion) may apply to the Court under s 31 of the COCA for an order placing the child under the guardianship of the Court. The Court may then override the parent's decision if the Court finds that such a course is in the best interests of the child.⁶⁹ In such a situation, Baragwanath recognised that the existing legislation represented:⁷⁰

a shift in policy from an emphasis on parental rights to exclusive focus on the rights of the child, the parents' position being assessed nowadays in terms not of rights but of responsibilities. Certainly the power of a parent as guardian includes decision making in relation to the child's medical treatment. *But the [COCA] emphasises that the welfare and best interests of the child are the sole focus of the consideration by the Court which may override parental views.* That does not however mean that the parents' interests and wishes are of other than very great importance. There is a presumption that they will receive effect and to the extent that they do not receive complete effect they will be recognised as far as is possible compatibly with the predominant interests of the child. That is because a child is not to be considered as a microcosm insulated from her parents but as far as practicable as part of the family of which she and they are the components.

⁶⁹ *Auckland District Health Board v Z* (2007) 26 FRNZ 596 (High Court) where the High Court held that it was in the child's best interests to have a life-saving blood transfusion, contrary to her parents wishes. The child in question was 4 years old.

⁷⁰ *Ibid* at [20] [Emphasis added].

For children unable to consent, parental authority includes a right to decide whether their child will undergo a genetic test⁷¹ as long as the test is in the child's best interests. In this manner, consent is justified by reference to the fact that the action was in the child's best interests. Some characterise the principle of best interests as limiting the scope of parental authority to consent,⁷² others describe it as justification for the provision of consent on behalf of the child.⁷³ Regardless of its precise characterisation, the "best interests" test provides the touchstone for what can and cannot be done to an incompetent child in a medical context.

The authority to consent is conferred on parents for the benefit of the child and not for the benefit of the parents.⁷⁴ The scope of parental authority does not preclude the child from expressing his or her opinion.⁷⁵ Section 16 of the COCA expressly acknowledges, consistently with international law, the evolving capacity of the child in defining a guardian's responsibility concerning *important matters* affecting the child as "determining for or with the child, or helping the child to determine" such matters.⁷⁶ Important matters include medical treatment which is not routine in nature.⁷⁷ In practice, although parental consent will be required to legally authorise a medical intervention for children not

⁷¹ See *Waikato District Health Board v F* HC HAM 4 December 2008, Andrews J at [75] where the High Court recommended that a genetic test be carried out on a seven year old child should the parents deem such a test appropriate.

⁷² *Marion's Case* above n 14.

⁷³ Beyleveld and Brownsword *Consent in the Law*, above n 33, 118.

⁷⁴ *Gillick*, above n 64, 170.

⁷⁵ The interplay between the principle of a child's best interests and the right of the child to express his or her wishes under Article 12 of the CRC will be discussed in Section 3 of this paper.

⁷⁶ Emphasis added.

⁷⁷ The COCA, s 16(2).

deemed to be competent at law, the closer the child is to the "competence threshold", the more involved s/he will be in the decision making and consent process. In recognition of the importance of recognising autonomy during childhood and affording respect to a child's views, children that fall short of full competence are still able to *assent* to medical treatment or procedures.⁷⁸

B. The child who is competent

This paper suggests that if a child is competent to consent then it is the child who has the authority to grant or refuse consent and who will be, unless expressed otherwise, in a confidential doctor-patient relationship to the exclusion of the parents.⁷⁹ Moreover, once a child has been deemed competent, no further limitation should be placed on the decision, particularly in the form of *best interests*. Although the decision maker is still a "child" for the purposes of the COCA, that decision maker is a *competent* child which demands that the best interests principle play no further role. The reasons for this view will be outlined below.

1. *Should best interests circumvent a competent child's decision?*

The decision in *Gillick* created some confusion as to the residual rights or responsibilities which parents retained notwithstanding their child being found competent. Both Lords

⁷⁸ HGRP, above n 4, 257. A health practitioner cannot rely on an incompetent child's assent in legally performing a medical procedure on that child. Valid consent from a competent party on the child's behalf is still necessary. The ability of a child to assent to a procedure, though of no legal effect, extends a degree of participation in the process to the child in question.

⁷⁹ In this situation, the competent child is in, for all intents and purposes, an analogous position to the competent adult. Medical law suggests that a legal power vests in the health practitioner to curtail the competent adult's decision on matters medical on limited (and unusual) public policy grounds: J Herring, *Medical Law* (Pearson Education Ltd, Essex 2008) 156. The precise nature of these criteria remain unarticulated and their application to competent children remains unexplored.

Scarman and Fraser were in agreement that all parental rights did not disappear until the age of majority.⁸⁰ However, Lord Scarman held that a parent's right to make a *medical* decision concerning a child was extinguished upon a finding that the child was competent to make that particular decision.⁸¹ Reliance on "residual parental rights" in the realm of children and medical decision making manifests itself legally by using the best interests standard to override a competent child's decision. In this way, best interests is relied on as a protective backstop to prevent a child's decision being given effect.

It is suggested here that their Lordships' views regarding the termination of general parental rights over their children does not support an argument that the best interests of the child should operate as an overarching limitation on a *competent* child's decision making in New Zealand. First, the entire concept of parental rights over children is outdated and has been ousted by the language of the COCA. Second, and in any event, for medical decision making, it was held that a finding of competence in turn required that parental rights to consent were terminated with respect to that decision.

It remains to be definitively decided in New Zealand whether a *Gillick* competent child's grant or refusal of consent can be subject to parental or judicial second-guessing via the child's best interests or some other standard. Across the Tasman, the NSW Law Commission, notwithstanding its support for a child's autonomy, has explicitly preferred a protective role for the law in health care matters and hence recommended retaining best interests as the limit on a competent child's decision making.⁸² Some have suggested that

⁸⁰ *Gillick* above n 64, at 171 per Lord Fraser and at 183-184 per Lord Scarman.

⁸¹ *Gillick*, above n 64, 188-189.

⁸² New South Wales Law Reform Commission, above n 66, 56.

the ultimate limitation of any decision is avoidance of serious harm.⁸³ This paper submits that it is inherently inconsistent to adopt an autonomy-based approach to the legal status of children while simultaneously allowing competent decision making by persons under 18 to be subject to a best interests limitation. Such an approach renders the autonomy of the child meaningless and fails to distinguish between competent and incompetent children: the best interests of the child is applied indiscriminately to both categories of children. Removing a best interests backstop for competent children does not render a judge powerless to intervene in a young person's decision. Rather, it should encourage a robust analysis of the child's level of competence.

The tenor of *Hawthorne v Cox* on this issue is promising. There, Heath J refused to invoke the Family Court's guardianship jurisdiction in respect of a 16 year old girl. Having examined in detail the statutory framework relating to the decision making of children, His Honour concluded that the presumption of competence engaged upon a child turning 16 has the effect of ousting, as a matter of law, a parent's ability to make *any* decisions for that child. Certainly, Heath J was not concerned with a child who had to satisfy the criteria of *Gillick* competence. Yet there is no reason for supposing that His Honour contemplated that a *Gillick* competent child would have to meet an additional threshold before his/her decision on a matter in which s/he was deemed competent was treated as conclusive. Viewed thus, *Hawthorne* comprises a broader statement that decision making power resides with those children deemed competent to make such decisions (either by satisfying

⁸³ In the United Kingdom, serious harm has been suggested as the ultimate limitation of a competent child's decision making: G Lansdown, *Taking Part: Children's Participation in Decision Making* (IPPR, London 1995). However, the English courts have not set the standard so high and parents may veto a child's decision simply on the basis of that they believe their course of action is in the child's best interests: *Re W (a minor) (medical treatment)* [1992] 4 All ER 627 (Court of Appeal) ("*Re W*").

Gillick or via the operation of statutory presumptions) with the role of guardian reduced to that of an advisor. Heath J's ventilation of the principles underpinning s 16(1) of the COCA ("Exercise of Guardianship") confirms this approach:⁸⁴

- (a) the younger the child, the more likely it is that decisions about important matters will need to be *made* by his or her guardian; and
- (b) as the child gets older and becomes more mature, the guardianship role changes to that of an advisor or a counsellor, endeavouring to assist the child to make good decisions.

Put in those terms, the Act is consistent with the philosophy underpinning *Gillick*, namely that a parent's interest in the development of his or her child does not amount to a "right" but is more accurately described as "a responsibility or duty". The terms of s 16 itself reflect that position.

2. *A distinction between a grant and a refusal to consent?*

The ability of a Court to override a competent child's decision can manifest itself in ways other than the employment of a best interests backstop. For example, in an attempt to avoid upholding a young person's decision to refuse life saving treatment, the English courts have held that *Gillick* competence only extends to consent to treatment, not refusal.⁸⁵ A distinction between the ability to consent to treatment and the ability to refuse treatment is illogical.⁸⁶ Freeman warns strongly against such a dichotomy and the attendant judicial retreat from the philosophy in *Gillick* that it represents.⁸⁷ The effect of the United Kingdom jurisprudence is to permit a person with parental responsibility to veto a competent child's refusal of consent while simultaneously empowering the court through

⁸⁴ *Hawthorne*, above n 62, [60] - [61].

⁸⁵ *Re R (a minor)* [1991] 4 All ER 177 (Court of Appeal).

⁸⁶ S Elliston, 'If You Know What's Good for You: Refusal of Consent to Medical Treatment by Children' in S McLean (ed) *Contemporary Issues in Law, Medicine and Ethics* (Dartmouth Publishing Company Ltd, Aldershot 1996) 34.

⁸⁷ M Freeman, 'Rethinking *Gillick*' (2005) 13 *The International Journal of Children's Rights* 201.

the application of the best interests principle to overrule that child's wishes.⁸⁸ That is so regardless of the child's age and demonstrated competence. This position sits awkwardly with the acknowledgment of the English Court of Appeal in *Re W* that the older the child, the greater the weight that should be placed on the child's wishes and that giving effect to those wishes is one way of recognising the paramount consideration of the welfare of the child.

The English path of retreating from a recognition of a competent child's ability to decide for him or herself has not been followed in New Zealand where a distinction has not been drawn between consent and refusal. The HGRP argues that in light of the COCA which sees consent and refusal to consent as two sides of the same coin, it is likely that a *Gillick* competent child's decision will be treated as final whether framed in terms of a refusal or grant of consent.⁸⁹ Indeed, the English approach for children under the age of 16 represents a wholesale undermining of the rights of children whom the law has deemed competent. In so doing, the United Kingdom position has systematically stripped the notion of *Gillick* competence of much of its normative force, implicitly rejected young persons as capable and autonomous human persons and rendered itself vulnerable to a charge of facilitating discrimination on the basis of age.⁹⁰

The English Courts have gone even further than the provision/refusal of consent distinction to undermine the health care decisions of competent children. English Courts have repeatedly ignored the express refusals of (clearly competent) children to undergo

⁸⁸ *Re W (a minor) (medical treatment)* above n 83.

⁸⁹ HGRP, above n 4, 303.

⁹⁰ Freeman, *Rethinking Gillick*, above n 87, 211-212.

significant medical procedures by subtly equating a child's best interests with prolonging that child's life.⁹¹ New Zealand courts should refrain from following this lead. Obiter comments from the High Court are encouraging evidence that New Zealand will not adopt such a narrow view of best interests:⁹²

While continuation of life is of great importance it is not necessarily conclusive; quality of life must also be considered. There must be a meticulous evaluation of the interests of the child, viewed broadly, and of that alone.

3. *Section 36 of the COCA - a potential limit on child decision making?*

In a *medical context*, s 36 of the COCA has introduced a potential fetter on the parameters of a child's consent to a treatment or procedure. Section 36(1) relevantly provides that a consent, or refusal to consent, to any medical, surgical or dental treatment or procedure to be carried out on the child *for the child's benefit*, if given by a child aged 16 or over, has effect as if the child were of full age. While pre-symptomatic genetic testing remains to be authoritatively legitimated as a "medical treatment or procedure" for the purposes of the COCA, its recognition as either a medical treatment or procedure is inevitable.⁹³ Given that pre-symptomatic genetic testing is caught by s 36, the italicised words have the potential to impose an additional obstacle on the ability of a person aged 16 or over to consent or refuse to consent to such a test. A literal reading of this provision would give rise to two anomalies. First, a minor aged 16 or over would have the right to refuse treatment that is to his or her benefit. Yet s/he would be unable to refuse treatment that is

⁹¹ *Re E (A Minor) (Wardship: Medical Treatment)* [1993] 1 FLR 386 ; *Re P (medical treatment: best interests)* [2004] 2 FLR 1117 (HC). See comments on this issue in J Bridgeman, *Parental Responsibility, Young Children and Healthcare Law* (Cambridge University Press, Cambridge 2007) 10.

⁹² *Auckland District Health Board v Z* above n 69, [22].

⁹³ HGRP, above n 4, 292-293.

not to his/her benefit.⁹⁴ Second, the decisions of persons deemed fully competent by statute would be subjected to more stringent restrictions than those of a child who was required to satisfy the *Gillick* competence test. For these reasons, the better view is to read the italicised words as redundant and conclude that a minor has the right to consent to or refuse treatment, whether it is to the minor's benefit or not.⁹⁵ In this regard, what is crucial is that the procedure or treatment is for the child and not someone else.⁹⁶ Therefore, as long as the child believes that the treatment or procedure is for his or her own benefit, the child's free consent will satisfy s 36. Such an interpretation aligns closely with the general principle of medical law that the right of self-determination of an autonomous person prevails over a conflicting medical opinion.⁹⁷

However, as the HGRP has acknowledged, it may be held that s 36 does limit a competent child's consent or refusal to consent to those medical treatments and procedures of benefit to him or her.⁹⁸ Consistent with the arguments above concerning a possible best interests limit on competent children's decisions, it is submitted that such a formulation fails to adequately recognise and respect a young person's competency and autonomy by introducing a justiciable criterion capable of trumping the young person's decision. Such

⁹⁴ HGRP, above n 4, 293.

⁹⁵ *Ibid* 293.

⁹⁶ It has been argued that the "benefit proviso" is aimed at preventing minors from consenting to non-therapeutic procedures such as organ donation, essentially because an organ donation is not a procedure for the child but for another: C Thomas, 'The Intolerable Dilemma: Refusal of Consent for the Medical Treatment of Children' (2000) 3 *Butterworths Family Law Journal* 173. This interpretation is interesting in light of the exception contained in Article 13 of the Genetic Testing Protocol to the Oviedo Convention which permits a derogation from the general rule that genetic testing should only be carried out for the health purposes of the person tested. This is discussed in greater detail in section three.

⁹⁷ G Tovey, *Nutcases Medical Law* (Sweet & Maxwell, London 2008) 56.

⁹⁸ HGRP, above n 4, 294.

an interpretation could perhaps be made more palatable if the expression "benefit" were interpreted broadly to include physical, psychological and emotional benefits.⁹⁹ In this regard, Skegg has noted that the s 36 reference to benefit:¹⁰⁰

is not qualified by 'health', 'bodily', or any such word, so other considerations could be taken into account. Furthermore, in other medico-legal contexts, the concept of 'benefit' has proved extraordinarily malleable.

The HGRP has detailed the benefits and harms involved in genetic testing and concluded that there is more evidence of benefits arising from genetic testing, particularly if the test is sought by the individual who is being tested.¹⁰¹ Indeed, if the test is sought by the young person him or herself, this in and of itself shows that the young person sees the testing as being beneficial.¹⁰² Therefore, as a general proposition, if s 36(1)(b) were limited by benefit, it would appear that young persons between the age of 16 and 18 could request and consent to a genetic test.

The above sketch of the New Zealand position should be sufficient to demonstrate three propositions. First, all persons aged 16 and over are presumed to be competent with the result that their refusal or grant of consent to a genetic test will be treated as both final and effective at law. There remains the possibility of a statutory "benefit" gloss being superimposed onto the refusal or grant of consent, which should be rejected for the

⁹⁹ This would only be a partial solution as the existence of any criteria, howsoever defined, provides an avenue to challenge an otherwise unchallengeable decision.

¹⁰⁰ PDG Skegg and R Paterson, *Medical Law in New Zealand* (Brookers, Wellington 2006) 171-203.

¹⁰¹ HGRP, above n 4, 295.

¹⁰² HGRP, above n 4, 295. Similar reasoning is adopted by Eekelaar in his argument for "dynamic self-determinism": Eekelaar, above n 39, 48. This argument will be discussed in the section on the child's views.

reasons already offered. Second, the decisions of all persons aged under 16 who are deemed *Gillick* competent in respect of that specific decision are final and effective at law. Finally, decisions affecting children who are not *Gillick* competent are made by a guardian which must act in the child's best interests. Insofar as genetic testing is concerned, it is this aspect of the law which the HGRP seeks to challenge. It argues that the guardian's authority to consent or refuse consent must be limited by what is for the child's benefit, rather than what is in the child's best interests.

SECTION TWO: THE BEST INTERESTS OF THE CHILD AND THE CHILD'S WISHES

PART 1: INTRODUCTION

At its core, human rights adjudication is about resolving conflicts of rights and interests.¹⁰³ Children's rights are not exempted from this rubric. This section will discuss two important international law principles relevant to the issue of parental authority to consent to the genetic test of their child: the best interests of the child; and the right of the child to express his or her views, and the application of these principles by the European Court of Human Rights.

For a child old enough to communicate his or her wishes, the right to express his or her views can be important in establishing the child's best interests.¹⁰⁴ A child who does not have the legal capacity to consent to a test retains the right to express his or her views. A child's wishes may conflict with the outcome that has been judged to be in the child's best interests. Such conflicts are common in the field of health care law in life-or-death treatment cases such as blood transfusions for Jehovah's witnesses and organ donations. True, these cases are a far cry from a family's decision about whether or not to have their young child genetically tested. Nevertheless, the choice to perform a genetic test can be a very important decision, particularly if the test is for an adult-onset disorder or to determine carrier status.

¹⁰³ S Besson, 'Enforcing the child's right to know their origins: contrasting approaches under the Convention on the Rights of the Child and the European Convention on Human Rights' (2007) 21 *International Journal of Law, Policy and the Family* 137.

¹⁰⁴ D Archard and M Skivenes, 'Balancing a Child's Best Interests and a Child's Views' (2009) 17 *International Journal of Children's Rights* 1, 15.

This section will begin by sketching the meaning of best interests in international law. This discussion will provide the background for an examination of how the principle of best interests has been relied on by the European Court of Human Rights. First, it will focus on how the best interests of the child and the Article 8 right to family life contained in the ECHR interact in practice. Second, it will analyse the manner in which the Strasbourg Court and European Commission on Human Rights have dealt with cases where the above provisions pull in opposite directions.¹⁰⁵ The final part will consider the child's right to express his or her views, in particular reconciling this principle with that of the child's best interests. Both the jurisprudence of the Strasbourg Court and New Zealand domestic courts will be examined.

PART 2: THE MEANING OF THE BEST INTERESTS OF THE CHILD

The principle of the best interests of the child, now regarded as the prevailing discourse with regard to the rights of the child, was conceived as a principle of Anglo-American family law, applied by courts and quasi-judicial bodies in the areas of matrimony, adoption, fostering and guardianship.¹⁰⁶ This traditionally paternalistic principle¹⁰⁷ has now been incorporated into the Child Convention,¹⁰⁸ a document which in many ways promotes a more autonomous view of the child, in line with a "self-determination" view of children's rights.

¹⁰⁵ At the time of writing, the Strasbourg Court has not dealt with the disclosure of genetic testing to children outside the realm of the identification of biological parentage.

¹⁰⁶ C Breen, *The Standard of the Best Interests of the Child: a Western Tradition in International and Comparative Law* (International Studies in Human Rights, Martinus Nijhoff Publishers, The Hague 2002) 9.

¹⁰⁷ In the sense that it involves a detached third party deciding, independently of the child who is primarily affected by the decision, what is best for that child without recourse to the child's views.

¹⁰⁸ The Child Convention, above n 5.

I. The Child Convention - Overview

The Child Convention, "the central international instrument on children's rights",¹⁰⁹ accords an extensive range of first generation and second generation human rights to persons under the age of 18 years. Due to its almost universal ratification, it can be cogently argued that parts of the Child Convention contribute to the fabric of customary international law.¹¹⁰ Yet, this does not mean, in light of the many reservations without corresponding objections, that the Child Convention in its entirety is customary law.¹¹¹ The CRC has not been incorporated into New Zealand domestic law. However, judges routinely draw on principles of the Convention¹¹² when making decisions while the best interests principle has been codified in s 4 of the COCA.

The CRC is based on four core principles: non-discrimination; the best interests of the child; the right to life, survival and development; and respect for the views of the child. The United Nations Committee on the Rights of the Child has classified the Child Convention's substantive provisions according to eight themes: the definition of the child; general principles; civil rights and freedoms; family environment and alternative care; basic health and welfare; education, leisure and cultural activities; and special protection measures.¹¹³ The Human Rights Committee emphasises that although the Convention is

¹⁰⁹ T Buck, *International Child Law* (Cavendish Publishing Limited, London 2005) 41.

¹¹⁰ Some parts of the Child Convention may simply be a codification of what was already customary international law, such as Article 37 which relates to torture.

¹¹¹ G Van Bueren, *The International Law on the Rights of the Child* (International Studies in Human Rights, Martinus Nijhoff Publishers, 1995) 55.

¹¹² A Brookers (Briefcase) search reveals over 200 New Zealand cases where the CRC has been referred to.

¹¹³ Human Rights Committee on the Rights of the Child, 'General Guidelines Regarding the Form and Content of Initial Reports to be Submitted by States Parties under Article 44, Paragraph 1(a), of the Convention' (UN Doc CRC/C/5, 1991).

split into different sections, equal importance shall be attached to each section.¹¹⁴ The *general principles* theme encompasses Article 2 *Non-discrimination*, Article 3 *Best interests of the child*, Article 6 *The right to life, survival and development* and Article 12 *Respect for the views of the child*.¹¹⁵ Articles 3 and 12 interrelate and, as should already be clear, are particularly germane to the issue of genetic testing of children.

II. Meaning of "The Best Interests of the Child" in International Law

Article 3 of the CRC provides that:

1. In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authoritative or legislative bodies, *the best interests of the child shall be a primary consideration.*
2. States Parties undertake to ensure the child such protection and care as is necessary for his or her well-being, taking into account the rights and duties of his or her parents, legal guardians, or other individuals legally responsible for him or her, and, to this end, shall take all appropriate legislative and administrative measures.
3. State Parties shall ensure that the institutions, services and facilities responsible for the care or protection of children shall conform with the standards established by competent authorities, particularly in the areas of safety, health, in the number and suitability of their staff, as well as competent supervision.

[Emphasis added.]

The article has been universally accepted as stated.¹¹⁶ Article 3(1) does not of itself create rights or duties,¹¹⁷ but appears to lend backbone to the other rights and duties contained in the Child Convention. However, this relationship is not entirely clear.¹¹⁸ The use of "a"

¹¹⁴ *Ibid.*

¹¹⁵ *Ibid.*

¹¹⁶ Unlike many other provisions in the CRC, no reservations have been made to Article 3.

¹¹⁷ See also M Freeman, 'Article 3: The Best Interests of the Child' in A Alen and others (eds), *A Commentary on the United Nations Convention on the Rights of the Child* (Martinus Nijhoff Publishers, Leiden 2007) 4. Van Bueren, above n 111, 46.

¹¹⁸ Freeman, 'Article 3: The Best Interests of the Child' above n 117, 4.

instead of "the" in defining "primary consideration" may have weakened the primacy of the principle and permits States to balance it against other considerations of equal importance.¹¹⁹ Van Bueren has queried the exact status of the best interests of the child in international law and whether it would take second place to "public policy".¹²⁰ Freeman argues that at the very least, the principle in Article 3(1) is both informed by and constrained by the rights and other principles in the CRC.¹²¹ An outcome which conflicts with other CRC rights cannot be said to be in the child's best interests.¹²²

Article 3(1) states that the child's best interests shall be a primary consideration for all actions concerning children taken by "public or private social welfare institutions, courts of law, administrative authoritative or legislative bodies". Freeman states that this does not apply to parents.¹²³ However, following a thorough examination of the drafting history of Article 3, Alston is not so convinced and provides three reasons why private actors may be covered.¹²⁴ First, Article 3(1) states a general principle (rather than prescribing duties) which should inform all decision making concerning children, including private family decisions. This argument is strengthened by the reference in Articles 18(1) and 27(2) of the CRC to parental responsibility in relation to the child. Secondly, the word "official" was deleted from the final version of Article 3(1) inferring that it was intended "to leave the

¹¹⁹ Van Bueren above n 111, 46.

¹²⁰ *Ibid* 48.

¹²¹ Freeman, 'Article 3: The Best Interests of the Child' above n 117, 5.

¹²² J Tobin, 'Beyond the Supermarket Shelf: Using a Rights Based Approach to Address Children's Health Needs' (2006) 14 *The International Journal of Children's Rights* 275, 287.

¹²³ Freeman, 'Article 3: The Best Interests of the Child' above n 117, 41.

¹²⁴ P Alston, 'The Best Interests Principle: Towards a Reconciliation of Culture and Human Rights' (1994) 8 *International Journal of Law and the Family* 1, 15.

door open" to its application to non-official entities as well. Finally, and related to the second point, the inclusion of the expression "private social welfare institutions" in Article 3(1) further indicates that it is not solely intended for public undertakings. The application in New Zealand of Article 3(1) to private actors, namely guardians, is moot in light of the express adoption of the best interests principle into s 4 of the COCA.

Little consideration tends to be afforded to the independent role that *best* plays in the determination of the composite expression "best interests". It fulfils an important role. Here, *best* is an adjective pertaining to the noun "interests", thereby modifying the effect "interests" has. *Best* requires that the path adopted not only be one in the child's interests but that it be in the child's *best* interests. *Best* is defined as "of the most excellent or desirable quality"¹²⁵ and denotes a measure of optimisation. This one simple word demands not just that the action in question yield a benefit to the child but that balance of benefits and detriments outweigh those of any other alternative course of action.

The principle of the child's best interests traditionally operated as a "self-imposed limitation on adult power".¹²⁶ It comprised an integral component of many domestic legal systems well before the promulgation of the CRC. Internationally, the principle was, to varying degrees, manifest in the UN Declaration of the Rights of the Child,¹²⁷ the UN Declaration

¹²⁵ C Soanes and A Stevenson (eds), *The Oxford Dictionary of English* (Revised edn Oxford University Press, Oxford 2005).

¹²⁶ Van Bueren above n 111, 45.

¹²⁷ United Nations Declaration on the Rights of the Child 1959 (GA/Res/1386(XIV) on 20 November 1959). The expression "best interests" was referred to in Principles 2 and 7.

on Social and Legal Principles relating to the Protection and Welfare of Children¹²⁸ and other treaties.¹²⁹

Somewhat incongruously, there was no mention of the child's best interests in the ECHR or the International Covenant on Civil and Political Rights.¹³⁰ Van Bueren attributes this omission to the perception that "the rights approach of human rights treaties is at odds with the traditional welfare approach of best interests which undermines the child's autonomy".¹³¹ A paternalistic principle of best interests (also known as a "relationship-based welfare approach")¹³² which served to curb a child's autonomy was the antithesis of the central goal of human rights treaties: to recognise each individual's dignity and autonomy.

It is here submitted, in line with arguments made elsewhere,¹³³ that the best interests of the child as formulated in the Child Convention has since moved away from a simple welfare, paternalistic and domestic law formulation of a child's best interests towards a broader and more complex principle of interpretation in international law. First, the CRC is a human rights treaty which has also incorporated the expression. This is, of itself, evidence of a shift away from the traditional concept of best interests since as we have seen above, a

¹²⁸ United Nations Declaration on Social and Legal Principles relating to the Protection and Welfare of Children, with Special Reference to Foster Placement and Adoption Nationally and Internationally 1985 (GA/Res/41/85 on 3 December 1986). See, e.g. Article 5.

¹²⁹ S Detrick, *A Commentary on the United Nations Convention on the Rights of the Child* (Martinus Nijhoff Publishers, The Hague 1999) 86.

¹³⁰ International Covenant on Civil and Political Rights 1966, opened for signature on 16 December 1966 (entered into force 23 March 1976) ("ICCPR").

¹³¹ Van Bueren, above n 111, 46.

¹³² J Fortin, *Children's Rights and the Developing Law* (2nd edn Lexis Nexis, Edinburgh 2003) 22.

¹³³ Van Bueren, above n 111. See also, Freeman, 'Article 3: The Best Interests of the Child', above n 117.

simple welfare and paternalistic principle is at odds with human rights.¹³⁴ Second, as a human rights treaty, it is arguable that its principles, including that of best interests, should be relevant to the interpretation of other treaties. Such an approach accords with the Preamble of the Vienna Convention of the Law of Treaties 1969¹³⁵ which recalls those principles of international law embodied in the UN Charter, including "universal respect for, and observance of, human rights and fundamental freedoms for all". Third, the reliance on the principle at the regional level, in particular the European Court of Human Rights, provides further evidence that it has become a general principle of international law, with strong interpretative value.¹³⁶ It is suggested that according such a broad interpretative role to Article 3(1) fulfils the three discrete uses predicted by Alston for the principle: one of supporting, justifying or clarifying a particular approach taken to CRC issues; one of mediating between (conflicting) rights; and, one of evaluating the laws and practices of the states parties in circumstances where positive rights are not in play.¹³⁷ Such roles are similar to those described by McCrudden for the application of the principle of dignity. This will be discussed further in the fourth section on dignity.

However, even if one accepts that best interests can properly operate as a general principle of interpretation in international law, the effectiveness and scope of such a principle remains unclear. Indeed, it has been argued that the best interests principle is plagued by a number of potential weaknesses. Some of these criticisms are cogent; others illusory.

¹³⁴ Van Bueren, above n 113, 46.

¹³⁵ Vienna Convention on the Law of Treaties 1969, 1155 UNTS 331 (entered into force 27 January 1980) ("VCLT").

¹³⁶ Alston, above n 124, 4.

¹³⁷ *Ibid.*, 15-16.

First, the application of the best interests principle requires some idea of its subject: the child.¹³⁸ Yet, the "child" as a legal notion is a societal construct. Society has arbitrarily decided that a child means every human being under the age of 18, unless the age of majority is attained earlier in accordance with the national law.¹³⁹ This arbitrariness has two related consequences. Most obviously, assumptions as to what a child is and the purposes underlining the separate legal treatment of children are concealed and creep uncontrolled into judicial analysis. Indirectly, the composite term the "best interests of the child" can be transformed into a clumsy rhetorical device capable of supporting any judicial decision on matters involving children without revealing the reasoning process which led to that result. This is not to presuppose that there is one universally correct outcome in each case involving a child's interests, howsoever defined. Rather, that rational justification and clarity of the debate demands that a transparent legal framework be available for determining what are inherently contestable claims concerning children. If assumptions about children are to be made, they should be revealed. If best interests is to be the cornerstone around which the jurisprudence in this area is organised, its requirements need to be laid bare. At a very minimum, this must involve the development of a clearer conception of the subject of this regime: the child.

Such a process is already underway in New Zealand where its courts have rejected a strictly age-based view of competence in favour of a more nuanced formulation. By looking behind the threshold of 18 years, in accepting that children of the age of 16 are presumed competent and children under 16 can still be deemed *Gillick* competent and

¹³⁸ Breen, above n 106, 18.

¹³⁹ The Child Convention above n 5, Article 1. In New Zealand the age of majority is 18.

able to make their own health care decisions the New Zealand Courts have gone some distance to assuage the above concerns. Instead of an arbitrary label, "child" has been turned into a highly fact sensitive construct which seeks to capture a complex balance between notions of reduced decision making ability and heightened parental responsibility.

Second, as a general interpretative principle in international law in matters concerning children, Article 3 does not explicitly resolve many fundamental questions, notably who decides on the allocation of decision making responsibilities between the child, the family and the state in particular circumstances.¹⁴⁰ The International Symposium on Bioethics and the Rights of the Child concluded that when interests differ, the child's best interests should, in principle, prevail over that of the adult.¹⁴¹ However, that rule of thumb offers no assistance in resolving a situation where what is regarded as being in the child's best interests conflicts with the child's wishes. This issue will be addressed below in the part on the child's views.

Third, the best interests principle is indeterminate.¹⁴² It is not defined with the CRC itself and its meaning was not even debated in the negotiation of the Child Convention.¹⁴³ There

¹⁴⁰ Breen, above n 106, 49.

¹⁴¹ J Danois, 'International Symposium: Bioethics and the Rights of the Child' (2000) Human Rights Defender 10.

¹⁴² Freeman, 'Article 3: The Best Interests of the Child' above n 117, 2.

¹⁴³ Ibid 26.

have been attempts to define best interests. For his part, Eekelaar defines best interests as:¹⁴⁴

Basic interests, for example to physical, emotional and intellectual care; developmental interests, to enter adulthood as far as possible without disadvantage; autonomy interests, especially the freedom to choose a lifestyle of their own.

The indeterminacy of the best interests principle permits "other principles and policies [to] exert an influence from behind [its] 'smokescreen'"¹⁴⁵ and provides a convenient cloak for bias, paternalism and capricious decision making.¹⁴⁶ It is this criticism of best interests which the HGRP emphasises to support its position: the ability for other considerations to be taken into account and usurp the child's interests regarding the genetic test. Such a concern is well-founded.¹⁴⁷ However, it is important not to overplay the indeterminate nature of best interests. For one, it is indeterminate because it is an international human rights norm which aims for universality.¹⁴⁸ Its indeterminacy "serves to emphasise the importance both of institutions as a means through which to pursue the [interpretative] enterprise and of the need to develop a better understanding of the different cultural dimensions of the relevant norms".¹⁴⁹ In any event, the scope of any indeterminacy is limited by two factors: the application of domestic norms and the terms of the Child Convention itself.

¹⁴⁴ J Eekelaar, 'The importance of thinking that children have rights' (1992) 6 *International Journal of Law and the Family* 221, 230-231.

¹⁴⁵ Freeman, 'Article 3: The Best Interests of the Child' above n 117, 2.

¹⁴⁶ S Parker, 'The Best Interests of the Child - Principles and Problems' (1994) 8 *International Journal of Law and the Family* 26.

¹⁴⁷ Some of the most difficult best interests cases relate to medical decision making: Freeman, 'Article 3: The Best Interests of the Child' above n 117, 3.

¹⁴⁸ Alston, above n 124, 18.

¹⁴⁹ *Ibid*, 18.

Fourth, and closely related to indeterminacy, the standard of best interests tends to be plagued by arbitrariness resulting in inconsistency of application, both domestically and internationally, the latter due predominantly to the numerous social and cultural variations which exist on the nature of "the child" and his or her best interests.¹⁵⁰ Like criticisms levelled at the arbitrary nature of the child, this seemingly reduces to a concern that best interests results in unsatisfactory legal opacity and becomes a vessel for the pursuit of interests extraneous to the child. Viewed thus, the best interests standard becomes meaningless, since it possesses "a complexity of contradictions, both in terms of interpretation and application".¹⁵¹

Fifth, a perceived problem of the best interests principle resides in the reality that what may be in the best interests of the child at the time of the decision making may quickly change - judges are unable to foresee all future circumstances which may operate to significantly alter the situation.¹⁵² However, there is nothing new in this. Dealing with probabilities rather than certainties is what judges do. When determining the applicable law in any given case, a trial judge is necessarily hazarding a prediction as to the law that an appellate court will apply should the case come before that court.¹⁵³ Moreover, many legal standards require a determination of what will occur in the future. When an injunction is sought on the grounds that "irreparable harm" will result if the defendant is permitted to continue in a course of action, the presiding judge must estimate the

¹⁵⁰ Breen, above n 106, 17.

¹⁵¹ *Ibid* 17.

¹⁵² *Ibid* 17.

¹⁵³ See generally: J Leubsdorf, 'The Standard for Preliminary Injunctions' (1978) 91 *Harvard Law Review* 525, 556.

magnitude of the respective irreparable harms suffered by the defendant (if the injunction wrongly issues) and the plaintiff (if it is incorrectly withheld). In such circumstances, a judge *ex ante* is making a decision which *ex post facto* can be shown to have irretrievably damaged legal rights. True, a child's future may not be involved,¹⁵⁴ but the point is that uncertainty in decision making within the legal system is ubiquitous and hardly new to judges.

Notwithstanding any criticism of the best interests principle, through the application of the CRC, it is a mandatory consideration to be taken into account at both domestic and international levels for matters concerning children. For all its flaws, the concept of "best interests" is not redundant. Yet the foregoing analysis should demonstrate that whatever legal formula we adopt to mediate the interface between children and medical decision making, it be clear, coherent and transparent.

PART 3: THE APPLICATION OF *BEST INTERESTS* IN THE EUROPEAN COURT OF HUMAN RIGHTS

I. The European Convention on Human Rights and the Charter of Fundamental Rights of the European Union

A. Overview and general principles of interpretation

Traditionally, the European Union has not had a "fully fledged" children's policy and EU law has been shaped by "the dominant ideology of the family and children's roles within

¹⁵⁴ However, in Hague Convention cases, injunctions could be obtained in proceedings to enjoin a parent from removing a child from the jurisdiction: Hague Convention on the Civil Aspects of International Child Abduction, concluded 25 October 1980 (Entered into force 1 December 1985).

the "the family".¹⁵⁵ This ideology pigeonholes family members into fixed roles, with parents having control over their dependent children, who lack individual autonomy.¹⁵⁶ Despite the wide ratification of the CRC, it was not until the late 1990's that the EU started to move away from the dominant ideology of the family and began to recognise that children are "competent, autonomous individuals, whose choices, views and values are to be heard and respected",¹⁵⁷ with interests that deserved protection.¹⁵⁸ In terms of the Council of Europe's approach, the European Convention focuses on rights of a civil and political nature and does not reiterate the Universal Declaration of Human Rights' standards of social and economic rights.¹⁵⁹ In this respect, the European Convention does not refer to the family as the natural and fundamental unit of society and lacks "even the most basic recognition of the rights of the child",¹⁶⁰ despite the fact that the family is generally regarded as a separate unit around which society is arranged.¹⁶¹

Two regional developments provided the catalyst for the dismantling of European reticence towards the rights of children.¹⁶² First, the Council of Europe's initiative of the European

¹⁵⁵ C McGlynn, *Families and the European Union : law, politics and pluralism* (Law and sociology, Cambridge University Press, Cambridge 2006) 42.

¹⁵⁶ *Ibid.*

¹⁵⁷ *Ibid* 43.

¹⁵⁸ *Ibid* 66.

¹⁵⁹ U Kilkelly, *The Child and the European Convention on Human Rights* (Programme on International Rights of the Child, Ashgate Publishing Limited, 1999) 2-3.

¹⁶⁰ *Ibid* 3.

¹⁶¹ Van Bueren, above n 111, introductory chapter at xxi.

¹⁶² In this respect "European" is referring to Europe's two main political organisations: the Council of Europe and the European Union.

Convention on the Exercise of Children's Rights¹⁶³ emphasised the applicability of the best interests principle in European law cases involving children.¹⁶⁴ The scope and object of the ECECR is set out in Article 1 which in relevant part provides:

The object of the present Convention is, in the best interests of children, to promote their rights, to grant them procedural rights and to facilitate the exercise of these rights by ensuring that children are, themselves or through other persons or bodies, informed and allowed to participate in proceedings affecting them before a judicial authority.

The ECECR emphasises the applicability of the best interests principle in Article 8 cases for those states that have ratified it. However, thus far it has not been widely ratified.¹⁶⁵ The Explanatory Report to the ECECR observes that it was intended to strengthen the substantive rights contained in the Child Convention by creating procedural rights that could be exercised by children themselves or through other persons or bodies.¹⁶⁶ Indeed, Freeman has described it as an attempt to "invigorate the provisions of the [Child Convention]",¹⁶⁷ but notes certain drawbacks: most of the protection is limited to children of sufficient understanding; and there are no rights to information, to be consulted or to express views.¹⁶⁸

¹⁶³ European Convention on the Exercise of Children's Rights, opened for signature 25 January 1996 (entered into force 1 July 2000) ETS No. 60 ("the ECECR").

¹⁶⁴ *Ibid.* The preamble of the ECECR explicitly cites the Child Convention and the best interests principle.

¹⁶⁵ As at 31 October 2008, 24 members have signed of which only 13 subsequently ratified. Member states that have not ratified this Convention include Belgium, the Netherlands, Norway, Switzerland and the United Kingdom. France, Germany, Ireland, Italy and Spain have ratified.

¹⁶⁶ Council of Europe, 'Explanatory Report to the European Convention on the Exercise of Children's Rights 1996' <<http://conventions.coe.int/treaty/en/reports/html/160.htm>> accessed 8 January 2009, para 7.

¹⁶⁷ Freeman, 'Article 3: The Best Interests of the Child' above n 117, 23.

¹⁶⁸ *Ibid.* 23.

Second, the adoption by the European Union of the EU Charter¹⁶⁹ in 2000 represented a commitment to provisions safeguarding children's rights and set out the principle of the best interests of the child. This Charter has broadened the European Union's jurisdictional scope from traditional economic and trade matters to include individual rights.¹⁷⁰ It is submitted that the latter development was the more significant for two reasons. First, the ECECR is rendered expressly subordinate to other treaties.¹⁷¹ Second, the Strasbourg Court does not supervise the ECECR. Rather, a "Standing Committee" is established to review its operation. Consistent with that relative importance, it has been argued that it was only when the Charter was adopted in 2000 that a "progressive approach to children and their rights entered into Union law and policy", with children finally being recognised as "independent subjects of Union law and policy, with their own particular needs and desires, separate from the interests of families, parents or other policy objectives".¹⁷²

The principle of the best interests of the child is contained in Article 24(2) of the Charter.¹⁷³ This codification within EU law has meant that for the first time children's interests are considerations in all areas of policy which "relate" to children.¹⁷⁴ In addition, the Charter has maintained the CRC wording that "best interests" is only "a" consideration which is to

¹⁶⁹ Charter of Fundamental Rights of the European Union [2000] OJ C 364("EU Charter")

¹⁷⁰ Wicks, above n 2, 7.

¹⁷¹ Refer Article 15 of the ECECR, above n 163.

¹⁷² McGlynn, above n 155, 67.

¹⁷³ The wording of Article 24(2) reflects Article 3(1) in a more summary form and provides that "in all actions relating to children, whether taken by public authorities or private institutions, the child's best interests must be a primary consideration". --

¹⁷⁴ McGlynn, above n 155, 69.

be balanced against other factors such as justice and society which, within the EU, "may give rise to unforeseen and potentially adverse consequences".¹⁷⁵

It is of course the European Convention itself which furnishes the practical link between rights and redress. Under its provisions, member states are obliged to "secure to everyone within their jurisdiction" the rights and freedoms of the European Convention and children have successfully brought cases before the European Court of Human Rights.¹⁷⁶ The rights in the European Convention are a source of general principles of European Community law.¹⁷⁷ The courts of member states have an overarching duty to construe legislation compatibly with Convention rights.¹⁷⁸ There are four general principles of interpretation of the European Convention that have arisen from Strasbourg Court jurisprudence. First, the Convention is to be interpreted purposively, in a manner consistent with its overall aims¹⁷⁹ resulting in rights that are "practical and effective" and not "theoretical and illusory".¹⁸⁰ Second, the European Convention shall be interpreted as a living instrument thereby maintaining its relevance to social and legal standards.¹⁸¹ Third, states have the benefit of

¹⁷⁵ Ibid 70.

¹⁷⁶ Van Bueren, above n 111, 22. The European Court of Human Rights, since the passage of Protocol 11 which came into force in November 1998, operates as a single Court of Human Rights and sits in Strasbourg on a permanent basis.

¹⁷⁷ HC Krüger, 'The European Union Charter and the European Convention on Human Rights: An Overview' in S Peers and A Ward (eds), *The EU Charter of Fundamental Rights: Politics, Law and Policy: Essays in European Law* (Hart Publishing, Oxford 2004) introduction at xxi.

¹⁷⁸ Buck, above n 109, 111.

¹⁷⁹ Ibid 114.

¹⁸⁰ *Airey v Ireland* (1979) 2 EHRR 305 ((ECtHR))

¹⁸¹ Kilkelly, above n 159, 13.

a margin of appreciation¹⁸² or a measure of discretion which is subject to the ultimate supervision of the European Court. When a balancing of rights is concerned, the margin of appreciation will be broad.¹⁸³ Finally, the European Court of Human Rights adopts the principle of proportionality requiring:¹⁸⁴

that the relationship between the means employed by a state to interfere with a right is proportional to the legitimate aims of such interference ... [such] an assessment requires an attempt to strike a fair balance between the demands of the general interest of the community and the protection of the individual's fundamental rights.

These four principles are of general relevance in determining how the best interests standard in the CRC (and in the Charter) and the right to respect for family life are reconciled by the Strasbourg Court in cases of conflict.

B. Reconciling the CRC and the European Convention in cases involving children

The precise legal relationship between the European Convention on Human Rights and the CRC depends greatly on the legal system of the state in question and the practical issue of enforcement. As a starting point, state parties are bound by the provisions of both the CRC and the European Convention.¹⁸⁵ Next, one must consider whether the state in question is dualist or monist.

If dualist, the general rule is that both the European Convention on Human Rights and the Child Convention remain part of international law unless specifically incorporated into

¹⁸² Ibid 6. Professor Kilkelly notes that the margin of appreciation is "frequently decisive of the scope of protection which the European Convention offers, particularly in children's cases". The principle of the margin of appreciation was explained by the European Court of Human Rights in *Handyside v UK* (1976) 1 EHRR 737 (ECtHR) [48]-[49].

¹⁸³ Besson, above n 103.

¹⁸⁴ Buck, above n 109, 114.

¹⁸⁵ VCLT, above n 135, Article 26.

domestic law.¹⁸⁶ Once incorporated, they have force of domestic law and any conflicts are to be reconciled using statutory interpretation. In dualist member states such as the United Kingdom and Germany, the European Convention has been incorporated into domestic law and has the force of statute. By contrast, the Child Convention has not been incorporated. This essentially creates a hierarchy between the two treaties, with the European Convention holding the primary position. Moreover, the CRC cannot be relied on directly by individuals in a dualist country as a basis for jurisdiction and no domestic court can assess a claim that a Child Convention right has been infringed.¹⁸⁷ Rather, the CRC will have effect as a relevant treaty to be taken into account in cases involving children, both at the domestic level and at the Strasbourg Court level.

If monist, then individuals within that state can rely on rights and/or duties contained in international treaties as if they were part of domestic law. Moreover, in some monist countries, treaties can override acts of Parliament.¹⁸⁸ For example, The Netherlands and France treat treaty law as prevailing over domestic law and the Dutch courts have used the European Convention to set aside Acts of Parliament. In theory, in monist jurisdictions,

¹⁸⁶ Granting a treaty legal effect in domestic law can be achieved in different ways. For example, in Italy, incorporation can be brought about by a constitutional law, an ordinary law, a presidential decree or an administrative act. There are two procedures available. The "special procedure" consists of an implementation order which provides that the entire Treaty is to apply without any changes in domestic law. The "ordinary procedure" requires substantive legislation incorporating the relevant treaty obligations. See generally: Council of Europe and British Institute of International and Comparative Law, *Treaty Making: Expression of Consent by States to be Bound by a Treaty* (Kluwer Law International, The Hague 2001) 92.

¹⁸⁷ Fortin, above n 132, 44.

¹⁸⁸ It is important to distinguish direct applicability from the status or "rank" an international treaty has once part of the domestic legal system. For example, in Italy (a dualist state), although the ECHR required a legislative act to lend it legal force, recent decisions of the Constitutional Court have granted it superiority over domestic statutes. See e.g. *Judgment No. 349 (24 October 2007) (Corte Costituzionale)* [2008] 17 International Yearbook of Italian Law 292 where a provision of domestic legislation was held to breach Article 1 of the Additional Protocol to the ECHR (concerning the protection of property) and therefore was deemed unconstitutional.

both the Child Convention and the European Convention have an equal status as two international treaties to which the states are parties. Individuals can directly rely on the CRC and European Convention rights and duties to base a claim in their courts. However, at the Strasbourg Court level, jurisdiction is founded solely in terms of the European Convention. On this stage, the Child Convention is only of secondary importance - as long as a decision is not inconsistent with the CRC, the state will be complying with its obligations under the Child Convention.

What then is the role of the Strasbourg Court in the protection of children's rights? The European Convention is not designed to deal with children's claims and is neutral on the delineation of the boundary between parental responsibility and children's rights.¹⁸⁹ Moreover, Article 8 ostensibly protects adults' privacy to the exclusion of that of children.¹⁹⁰ A primary concern, which has already been recorded, is the lack of a best interests principle within the European Convention.

However, the open-textured nature of Article 8 has the capacity to enhance the protection which it offers children.¹⁹¹ Indeed, broadly-framed provisions such as Article 8 are routinely employed to protect children and although the Strasbourg Court could have continued down a line of favouring parents, it has not done so.¹⁹² Its interpretation of Article 8 is discussed in the next section.

¹⁸⁹ Fortin, above n 132, 53 -54. Indeed, the Convention's focus is civil and political rights.

¹⁹⁰ Ibid 54.

¹⁹¹ Kilkelly, above n 159, 13.

¹⁹² See *Johansen v Norway* (1996) 23 EHRR 33 (ECtHR) ("*Johansen*").

Professor Kilkelly emphasises that the European Convention, as a system of human rights protection, cannot and does not in practice, operate in isolation from surrounding legal and social influences. In this respect, the Strasbourg Court relies on factors outside the European Convention, including those legal instruments and treaties which make up regional and international human rights law.¹⁹³ Both the CRC and the Charter are obviously important developments to the application of the European Convention to children. In situations where the European Convention is silent, the CRC provides a "clear and comprehensive code of children's rights".¹⁹⁴ Provided that any adoption of the Child Convention principles produce a result that is compatible with the object and purpose of the European Convention, relying on the CRC is "entirely acceptable".¹⁹⁵ It is also suggested that even when the European Convention is not silent, the Charter and the general principles of the CRC are relevant considerations in matters concerning children.

C. The scope of Article 8 of the ECHR

Article 8(1) sets out the scope of the substantive right and includes two central expressions "family life" and "private life". Article 8(2) sets out a broad catalogue of permissible interferences with that right. The European Court of Human Rights has interpreted the expression "family life" broadly to include *de facto* family life, thereby protecting a tie between near relatives such as grandparents and grandchildren.¹⁹⁶ The expression "private life" has been drawn in a similarly broad fashion, yet the Court has stopped short of

¹⁹³ Kilkelly, above n 159, 14-15.

¹⁹⁴ *Ibid* 15.

¹⁹⁵ *Ibid* 115-16.

¹⁹⁶ Van Bueren, above n 111, 70. See also *Kroon and Others v The Netherlands* (1994) 19 EHRR 263 (ECtHR) [30].

formulating an exhaustive definition.¹⁹⁷ Certainly, "private life" encompasses the physical and moral integrity of a person and captures a medical intervention, such as a blood test required in paternity actions.¹⁹⁸ It also includes access to, and the protection of, personal information¹⁹⁹ and medical data.²⁰⁰ Although Article 8(2) clearly sets out the negative obligations on states, the right to private life has been interpreted as imposing positive obligations, including, in one instance, an obligation on the national authorities to facilitate a reunion between family members.²⁰¹ Children must also have rights under Article 8 and it has been argued that an outcome which is contrary to a child's best interests is a breach of the child's right to respect for family life under Article 8.²⁰² It was recognised early on, by the European Commission on Human Rights, that a child's best interests could operate as a justified limitation of a parent's right of access to his child under Article 8 of the ECHR.²⁰³ In limiting or even overriding a right of a parent under the ECHR, the Strasbourg Court has explicitly noted that "a parent cannot be entitled under

¹⁹⁷ See generally *Friedl v Austria* (1996) 21 EHRR 83 (European Commission on Human Rights), *Peck v United Kingdom* (2003) 36 EHRR 41 (ECtHR), *Niemitz v Germany* (1992) 16 EHRR 97 (ECtHR). Arguably, Courts are comforted by the availability of a broad residual right which deserving claims can be shifted into when the wording of more precise provisions does not apply. This could explain the failure to exhaustively define the parameters of "private life".

¹⁹⁸ Buck, above n 109, 116.

¹⁹⁹ *Gaskin v United Kingdom* (1989) 12 EHRR 36 (ECtHR).

²⁰⁰ *Z v Finland* (1997) 25 EHRR 371 (ECtHR).

²⁰¹ *Hokkanen v Finland* (1994) 19 EHRR 139 (ECtHR) ("*Hokkanen*").

²⁰² See The Netherlands submissions in *Hendriks v The Netherlands* (1982) 5 EHRR 223, E Com HR 8427/78 (European Commission of Human Rights) ("*Hendriks*").

²⁰³ *Hendriks*, above n 202.

Article 8 of the Convention to have such measures taken as would harm the child's health and development".²⁰⁴

However, there remain both procedural and substantive problems with the Strasbourg Court's approach. Fundamentally, it characterises the best interests of the child as informing the justified limitation question rather than fashioning the content of the Article 8 right. The difference between the two processes is more than semantic. The former approach necessarily results in any consideration of the best interests of the child taking place in the context of a *prima facie* infringement of an adult right. That Article 8(2) calls upon the state to justify the infringement immediately places the best interests of the child on the back foot. A presumption that the adult's application should succeed is effectively imposed before the child's interests are even considered. The latter approach avoids the best interests of the child being hijacked by the rhetoric of an established rights infringement. In this way, the best interests of the child and the pleaded interests of the relevant adult engage on an even playing field, devoid of any *de facto* presumptions, in determining whether an Article 8 right is even triggered and, if so, what the precise nature of that right is.

Procedurally, there are evidential differences between the requirements of Article 8 of the ECHR, Article 3 of the CRC and domestic legislation which incorporates the paramountcy principle such as the Children Act 1989 (UK).²⁰⁵ One cannot simply argue that an outcome runs foul of the child's best interests and leave it at that. If a parent has argued that a particular order violates his or her Article 8 right, then the Court must justify such an

²⁰⁴ *Johansen*, above n 192, at [210].

²⁰⁵ Fortin, above n 132, 59.

infringement rather than simply disregard it as the CRC or the paramountcy principle would dictate. Article 8 appears to revive a concept of parental rights which up until now had been considered outdated.²⁰⁶ Fortin acknowledges that the outcome will often be the same under an Article 8 analysis and a paramountcy principle approach, but not always.²⁰⁷

Substantively, Freeman and Fortin argue that by placing the child's interests within Article 8(2), the Court has failed to recognise children as being individual players with rights of their own.²⁰⁸ In this manner, the Strasbourg Court has overlooked the European Convention's Preamble which affords "equal and inalienable rights of all members of the human family".²⁰⁹

In Article 8 cases, the applicant will have to argue that the case falls within the scope of the right under Article 8(1) and that there has been interference of some sort. It will then be for the state to show that the interference was justified. In this second stage, the Court will examine the nature of the interference, the legal basis for the interference, the legitimate aims of the interference and the necessity of the interference in a democratic society.²¹⁰ Having conducted a thorough survey of relevant case law, Fortin has concluded that in cases where the interests of the parent and child conflict, the Court can restrict a parent's rights by reference to the child's best interests as long as (a) the parents have been fully involved in the decision making process; (b) the restriction is proportionate

²⁰⁶ *Ibid* 59.

²⁰⁷ *Ibid* 59.

²⁰⁸ Freeman, 'Article 3: The Best Interests of the Child' above n 117, 14. Fortin, above n 132, 59.

²⁰⁹ Freeman, 'Article 3: The Best Interests of the Child', above n 117, 14.

²¹⁰ Buck, above n 109, 117-118.

to its legitimate aim; and (c) a fair balance has been struck between the competing interests (which may include third parties) of all concerned.²¹¹

From the foregoing it is clear that when considering whether a genetic test should or should not be authorised, there is an underlying tension between the rights of the child, the rights and duties of family members and the responsibilities of the state (usually through the adoption of legislation). Similar tensions have emerged in custody/access cases and identity cases.

1. *Select custody/access cases*

Custody cases require an interpretation of the parents' right to respect for family life which is consistent with the best interests of the child as set out in the CRC and the Charter. Prior to the Child Convention, the best interests of the child was a relevant consideration in deciding Article 8 cases. In *Hendriks v The Netherlands*,²¹² the applicant, a Dutch national, brought proceedings in the Dutch courts to gain legal access to his son. His ex-wife refused to agree to any access. Mr Hendriks' claim turned on whether the relevant Dutch legislation was consistent with his Article 8 right to family and, if so, whether the national courts' interpretation of that law in his case was consistent with his right.²¹³ Only the second issue will be examined here. The Dutch courts had consistently (and astonishingly) held that although the starting point was that contact with both parents was

²¹¹ See *Johansen* above n 190 for the notion of fair balance; *Hokkanen* above n 201 at [58] where the Strasbourg Court held that in interpreting Article 8(2), the rights and freedoms of all concerned must be considered.

²¹² *Hendriks*, above n 202.

²¹³ Section 161(5) of the Dutch Civil Code provided that "The Court may on the application or request of both parents or of one of them make an arrangement for contact between the child and the parent to whom the custody has not or will not be awarded ...".

preferred (as this would normally be in the child's best interests), when the *custodial parent* refused to co-operate then the best interests of the child favoured a denial of contact to the *non-custodial parent*.

The Commission concluded that the applicant's right of access under Article 8(1) had been interfered with by the courts' interpretation of the provision but was justified under Article 8(2) because the interference was in accordance with the law;²¹⁴ had legitimate aims, being for the protection of the child;²¹⁵ and was necessary in a democratic society for the protection of the health of the child.²¹⁶ The Commission pointed out that in the realm of custody law and the refusal of a right to access the legitimacy of an interference with Article 8 had always been interpreted so that the interests of the child predominated.²¹⁷ In accepting that the denial of access was necessary, the Commission accorded the domestic courts' a significant margin of appreciation,²¹⁸ and concluded that the protection of children was an important function of the law in a democratic society.²¹⁹ The Commission held that whenever there was a conflict between the interests of the child and the parent in such cases, the child's interests had to prevail under Article 8(2).²²⁰

²¹⁴ *Hendriks*, above n 202, [113]-[114].

²¹⁵ *Ibid* [118].

²¹⁶ *Ibid* [125].

²¹⁷ *Ibid* [115].

²¹⁸ *Ibid* [118].

²¹⁹ *Ibid* [120].

²²⁰ *Ibid* [124].

It is submitted that the Commission's decision reveals an institutional fidelity to the traditional welfare approach to best interests²²¹ in two respects. First, the best interests of the child was not used to interpret the substantive right itself as set out in Article 8(1). Second, the European Commission in its Article 8(2) analysis was content to defer to the national courts' judgment on the best interests of the child, notwithstanding that those judgments comprised a wholesale substitution of their views for that of the child. Indeed, at no point in the appellate proceedings were the child's views on contact with his father expressly sought (although evidence was adduced to the effect that the child was content with his mother and step-father).²²²

Post Child Convention, it appears that the Strasbourg Court's approach in custody cases remains unchanged. In *Görgülü v Germany*²²³ the European Court of Human Rights echoed the European Commission's views in *Hendriks*, holding that the principle of best interests of the child was relevant in terms of determining whether interference with Article 8(1) is necessary in a democratic society but did not rely on the CRC for this conclusion. The Court did differ to the *Hendriks* Court by piercing the margin of appreciation and examining in detail how Germany had struck that balance. It found unanimously that the child's interests had not been adequately taken into account in failing to grant custody to the child's father.

²²¹ Rather than using the child's best interests principle as an interpretative tool as now required under Article 3 of the Child Convention.

²²² The child had not seen his father since birth which at the time of the proceedings amounted to a period of 4 years.

²²³ *Görgülü v Germany* [2004] ECHR 89 (ECtHR) ("*Görgülü*").

2. *Select identity cases*

The balancing of the child's best interests against the interests of his or her parents has been most recently discussed in the context of a child's right to know his or her genetic identity as protected by both Articles 7 and 8 of the CRC and Article 8 of the European Convention. In this regard, the child's right to know conflicts with many other rights: "one may think for instance, of the competing rights to autonomy and privacy of the mother, the father, the adoptive parents or the gamete donor".²²⁴ Some European nations permit immediate release of the information while other countries' laws provide it once the child has turned 18. Ultimately, the release of a child's genetic heritage is controlled according to the child's best interests.²²⁵ In addition to the Article 8(2) criteria for justified interference, it is argued in identity cases that respect for the right's inner core need also be maintained.²²⁶ A violation of a right's inner core would deprive the right of its very essence thereby emptying it of any content. Theoretical difficulties arise under this approach when two rights are brought into conflict with one another. Should each right threaten the respective inner core of the other, a Court can be tasked with an impossible balancing exercise.²²⁷

²²⁴ Besson, above n 103.

²²⁵ *Ibid.*

²²⁶ *Ibid.*

²²⁷ *Ibid.* In practice the inner core of the right is a malleable construct employed for no greater purpose than a reminder that rights are not to be traded away entirely by consequentialist limitations. It would be unlikely that a Court would conclude that two conflicting rights cannot be resolved without the inner core of one having to be disturbed. This would be contrary to the very structure of the European Convention which posits a hierarchy among the specific rights articulated in the text.

The Strasbourg Court in *Odièvre v France*²²⁸ and *Jäggi v Switzerland*²²⁹ has taken two different approaches to reconciling the inner conflict created by Article 8 in adoption cases which seeks to mediate a child's right to identity and the parent's right of confidentiality. In *Odièvre*, the Court by 10 votes to 7, held that there had been no violation of Ms Odièvre's right to respect for family life committed by the French practice of anonymous birth. The applicant, an adult at the time of the litigation, relied on the fact that France's practice of anonymous birth was unique amongst the European member state, arguing that a state could not be afforded a margin of appreciation in circumstances where, despite the best interests of the child being at stake, it maintained a different stance to the overwhelming consensus within the members states of the Council of Europe.

The Court emphasised the many interests to be balanced: the child's right to know her identity; the birth mother's interest in remaining anonymous in order to protect her health; and the interests of the adoptive parents.²³⁰ It reiterated that there were different ways in which a state could ensure respect for private life, whilst acknowledging that France was unique insofar as it sanctioned a permanent inability of an adopted child to establish his or her origins.²³¹ The Court (in failing to mention the CRC) held that France had sufficiently balanced the competing interests and not breached Article 8 for two reasons. First, the applicant had been given access to non-identifying information about her natural mother.

²²⁸ *Odièvre v France* (2004) 38 EHRR 43 (ECtHR) ("*Odièvre*").

²²⁹ *Jäggi v Switzerland* 13 July 2006, ECHR, 58757/00 (ECtHR) ("*Jäggi*").

²³⁰ *Odièvre* above n 228, [44].

²³¹ *Ibid* [46]-[47].

Second, new legislation permitted an independent body to waive confidentiality if the birth mother consented.

The minority subjected the majority's analysis to robust criticism. By hiding behind the principle of margin of appreciation the dissenters argued that the Court had failed in its duty to review the way in which France had balanced the rights at stake. The practical effect of the decision was to confer an absolute right upon French birth mothers, in direct contravention of the child's right's inner core,²³² which clearly included *the right to an identity*, an essential condition of the right to autonomy. Put simply, the majority had not attributed the proper scope to Article 8(1). Finally, the majority had failed to take into account important international conventions such as the Child Convention, in particular Article 7.

In *Jäggi*, the Court revised its approach taken in *Odièvre* and found, by 5 votes to 2 that there had been a violation of Article 8. The Court held that the right to know one's parentage was part of the inner core of the right to private life²³³ and concluded that Switzerland had not balanced the relevant interests correctly thus breaching Article 8.²³⁴

3. *Synthesis of approaches*

Hendriks and *Görgülü* suggest that in custody and access cases, a child's best interests only remain relevant in terms of the Article 8(2) balancing test, rather than supplying the content of the substantive right. Yet the centre of gravity may be shifting. Certainly, in cases

²³² *Odièvre*, above n 228, [11].

²³³ *Jäggi*, above n 229, [37].

²³⁴ The minority disagreed on this point and did not think that the balancing had been so clearly wrong as to justify a finding of a violation: *Ibid*, see Dissenting Opinion.

involving the right to know one's parentage (which comprise the more recent line of cases), the trend of the Strasbourg Court is to resolve the tension between a child and a parent's rights, by determining the right's so-called "inner core" under Article 8(1) and then in light of that, balancing the competing interests under Article 8(2). This may be the genesis of a more broadly based and pervasive shift in the European Court of Human Rights' thinking on children's rights. Yet it is too soon to confidently tell. Somewhat surprisingly, the two bodies of case law, custody and access on the one hand and parentage on the other, do not talk to each other. Were they to do so, it is argued that the more "front-end" oriented analytical approach adopted in parentage cases should, for the reasons offered, become the general analytical blueprint for the Strasbourg Court in all matters concerning children.

PART 4: THE CHILD'S RIGHT TO EXPRESS HIS OR HER VIEWS

The Article 12 right of a child to express his or her views is one of the four core principles of the CRC and is sometimes referred to as the child's right to self-determination.²³⁵ It is generically referred to as the child's right to be heard.²³⁶ In any case where an action may affect the child, the best interests of the child shall be a primary consideration with the child entitled to express his or her views in relation to the action in question. Much has been written on the balance to be struck between a child's best interests and a child's views.²³⁷ In many cases the child's wishes will conflict with what is ultimately perceived

²³⁵ N Thomas and C O'Kane, 'When children's wishes clash with their 'best interests'' (1998) 6 *The International Journal of Children's Rights* 137.

²³⁶ Human Rights Committee on the Rights of the Child, 'General Comment No. 12 (2009): the Right of the Child to be Heard (Un Doc CRC/C/GC/12)' (2009).

²³⁷ See, e.g. Eekelaar, 'The Interests of the Child and the Child's Wishes: the Role of Dynamic Self-Determinism' above n 39; Thomas and O'Kane, 'When children's wishes clash with their 'best interests'' above n 235; Freeman, 'Article 3: The Best Interests of the Child' above n 117; Archard and Skivenes, above n 104.

as being in the child's best interests. The central question is how to resolve such a conflict. This requires consideration and reconciliation of, on the one hand, adult duties to promote the child's best interests and to listen and consider the child's wishes, and, on the other hand, a child's right to protection and participation.²³⁸ This part will examine the meaning afforded to Article 12 (or a domestic variation thereof) by the Strasbourg Court as well as in New Zealand domestic law, focussing primarily on its interaction with the principle of best interests.

I. Reconciling a Child's Views and His or Her Best Interests

Article 12 of the Child Convention grants those children who are capable of forming their own views, the right to freely express those views in matters affecting them. Those views are to be given due weight, in accordance with the child's age and maturity. The commitment is to hear the child and to give the views a weight proportionate to the child's maturity. Despite the absence of a clear hierarchy amongst the provisions in the Child Convention, Article 12 tends to be subjugated to the principle of best interests in domestic legal systems.²³⁹

It has been argued that the qualification of "age and maturity" in Article 12 permits the child's views to be ultimately disregarded or more easily outweighed by other considerations.²⁴⁰ Here, the concern is that the right to express one's views is hollow if those views can be simply disregarded by conclusory resort to the child's "best

²³⁸ Thomas and O'Kane, 'When children's wishes clash with their 'best interests'' above n 235, 139.

²³⁹ Archard and Skivenes, above n 104, 2.

²⁴⁰ Thomas and O'Kane, 'When children's wishes clash with their 'best interests'' above n 235, 138.

interests".²⁴¹ As we have seen in the earlier part on competence, this situation is exacerbated in the case of a competent child whose views are disregarded in the name of *best interests*. Framing the issue in this way exposes the close relationship that the child's best interests and respect for the child's views has in practice. Freeman suggests that the answer is one of balancing autonomy and best interests.²⁴²

Eekelaar provides a model of how to achieve such a balance called dynamic self-determinism.²⁴³ His model restructures the concept of best interests so as to coalesce with the proposition that children are rights-holders. He notes that the best interests principle is usually employed in a process of "objectivisation" whereby the decision-maker draws on beliefs as to what is in the child's best interests such as expert evidence and his or her own social beliefs.²⁴⁴ The reliability of such determinations is uncertain.²⁴⁵ Eekelaar's alternative is to eschew reliance on the decision maker's beliefs of the child's best interests on a largely predictive basis and instead defer a final determination by the decision maker until the child has been observed in his or her own "reasonably secure" environment.²⁴⁶ As the child develops, s/he is encouraged to draw on these influences so as to ultimately contribute to the outcome: "the very fact that the outcome has been, at least partly, determined by the child is taken to demonstrate that the outcome is in the child's best

²⁴¹ Freeman, 'Article 3: The Best Interests of the Child' above n 117, 6.

²⁴² Ibid 6.

²⁴³ Eekelaar, 'The Interests of the Child and the Child's Wishes: the Role of Dynamic Self-Determinism' above n 39.

²⁴⁴ Ibid, 46- 47.

²⁴⁵ Ibid, 47.

²⁴⁶ Ibid, 48.

interests".²⁴⁷ Eekelaar acknowledges that such a result would be a strain on resources, but only in the "most conflicted of cases".²⁴⁸ The passive role this process accords to the child has been criticised for its failure to emphasise the child's right to participate and enter into a process of dialogue with the adults involved.²⁴⁹ Where genetic testing is concerned, genetic counselling may fulfill the role of "dynamic self-determinism" and simultaneously address the criticism regarding a child's participation (or lack thereof) in the process.²⁵⁰

A common theme regarding the best interests of the child, the child's views, and medical decision making, is the tendency to collapse the questions of the child's capacity and his/her best interests into one enquiry.²⁵¹ In this way, a child's capacity is determined by reference to an assessment of the child's best interests: if the child's views conflict with his or her best interests, this often leads to a conclusion that the child does not have the capacity to make the decision at all.²⁵² The discussion in section two of this paper should be sufficient to illustrate the problems in such an approach. Competent children, it has

²⁴⁷ Ibid, 47-48.

²⁴⁸ Ibid, 48.

²⁴⁹ Thomas and O'Kane, 'When children's wishes clash with their 'best interests'' above n 235, 141.

²⁵⁰ Genetic counselling has been defined as "a communication process dealing with the human problems associated with the occurrence, or the risk of occurrence, of a genetic disorder in a family": A Clarke, *The Genetic Testing of Children* (Bios scientific publishers, Oxford 1998). The main aim of genetic counselling is to personalise appropriate genetic information about the risk or potential for disease. The central elements include risk assessment, information-giving, decision making and assessment of psychological coping processes. Generally, a consultation will include the nature of the disorder, the family history and an assessment of the individual. It is to be distinguished from a medical consultation in its emphasis on knowledge. It does not focus on the "is" but on the "might be": refer C Evans and B Biasecker, *Genetic Counselling: a Psychological Conversation* (Cambridge University Press, Cambridge 2006).

²⁵¹ This approach is seen in the Oviedo Convention, above n 7, which also appears to collapse the issue of capacity and best interests at the first stage, with benefit coming in at the second stage: see Section 3.

²⁵² A further distinction is often overlooked in medical decision making where the question of what is medically best for the child (an empirical issue) is typically equated to the child's best interests (a more complex normative issue): Archard and Skivenes, above n 104, 9.

been argued, should be able to make decisions with which others disagree and perceive to be against their best interests. Certainly, a child's maturity or capacity should be decided independently of an evaluation of the child's views. However and consistently with Eekelaar's characterisation of a child's competence, the perceived wrongness of a child's views (or life goals) can be evidence that the child is not competent.²⁵³

II. The Strasbourg Court and Article 12 of the CRC

The Strasbourg Court has not, as it has done with the principle of best interests, read in the requirement of respecting the child's views into the ECHR. In some cases, affording the child's views with more respect may have led to a different (and preferable) result.²⁵⁴ Such an approach may be reflective of the differing status of best interests and the child's views, the latter not always finding expression in domestic law.

However, in more recent case law, the Strasbourg Court has recognised that the child's wishes can be relevant in determining whether measures adopted by the state are "necessary" under Article 8(2).²⁵⁵ In *L v Finland* two children, P and S were placed into a foster home by the state. Through a series of official decisions the state adopted severe restrictions on the applicants' (father and grandfather) access to the two children. The initial taking into care and the subsequent orders made in relation to their care, namely that P and S remain in a foster home and see their parents a limited number of times a year

²⁵³ *Ibid*, 10.

²⁵⁴ See e.g. *Nielsen v Denmark* (1988) 11 EHRR 175 (ECtHR). Here the placement of a 12 year old in a closed psychiatric ward, at his mother's request and against his express wishes and the fact that he did not suffer a mental illness, was not held to have breached Article 5 (right to liberty and security) of the ECHR. Note that this decision was decided prior to the CRC coming into force.

²⁵⁵ *L v Finland* (2001) 31 EHRR 30 (ECtHR) at [125].

were claimed to be breaches of the applicants' Article 8 right. The relevant Finnish legislation recognised the importance of ascertaining the child's views when determining access and custody affecting that child. P and S did not want more regular access to the father-applicant, and wanted no access with their grandfather. The Strasbourg Court held that the violation of the applicants' Article 8 rights (which was conceded by Finland) was justifiable under Article 8(2) as they were in accordance with the law and were necessary in light of the facts of the case, including the children's views.

III. New Zealand and the Child's Wishes

New Zealand expressly recognises the relevance of a child's views. However, under s 6 of the COCA, this is limited to proceedings concerning guardianship, custody, and the child's property. Section 6 provides that in such proceedings, a child has to be given a reasonable opportunity to express his or views and that any views must be taken into account. The section, contrary to Article 12 of the Child Convention, is silent as to the weight to be afforded to the child's views.

There is no provision which sets out the child's right to express his or her views in other contexts. Yet this does not oust the legal obligation to obtain the child's views in medical decision making where guardianship is not at issue. First, the construction of s 16 "exercise of guardianship" provides that medical treatment decisions for children unable to consent themselves are to be determined "for or with the child". Second, the rights provided to health consumers in the Code expressly include a right to effective communication. Finally, the common law recognises the right of a child to express his or her views, although there are few cases where the child's views deviate significantly from

his/her best interests in a medical context.²⁵⁶ One case concerned the genetic testing for parentage purposes of an eight year old.²⁵⁷ The applicant in the Family Court proceedings alleged he was the father and applied for a genetic test to be carried out. Genetic testing to determine parentage can be ordered by the Court pursuant to s 54 of the Family Proceedings Act 1950. The child was vehemently opposed to the testing. The proceedings engaged s 6 of the COCA as the guardianship of the child was ultimately at issue. On appeal against the Family Court's decision ordering the test, the High Court held that the age and maturity of the child were factors (amongst others) relevant to the weight to be given to the child's views, just as with any other evidence before the Court. However, Heath J agreed with prior case law²⁵⁸ that the proper construction of s 6(2) did not demand that a child's views expressed under s 6 be determinative. Such a conclusion would run counter to the overarching obligation of the Court under s 4 to act in the child's best interests. Despite the child's views, the Court concluded that the parentage test was in the best interests of the child.²⁵⁹

²⁵⁶ It is worth mentioning that in a case involving the medical treatment to be given to a very sick seven year old, the child's views were not expressly mentioned. A lawyer for the child was appointed and cross examined the doctors who were defending the proposed treatment but at no point were the child's views discussed. In that case, a genetic test (for diagnostic purposes) was recommended if the parents deemed it appropriate with no mention of the child. See *Waikato District Health Board v F* above n 71.

²⁵⁷ *Fletcher v Blackburn* [2009] NZFLR 354 (High Court).

²⁵⁸ *C v S* [2006] 3 NZLR 420 (HC).

²⁵⁹ The Court allowed the appeal on the grounds that the Family Court had "gone too far" by, in response to the child's mother being consistently uncooperative, immediately placing the child under the guardianship of the Court for the purposes of the genetic test being carried out. The Family Court should have granted the mother one last chance to arrange for the test to be carried out, thereby avoiding such a coercive environment for the child: *Fletcher v Blackburn* above n 257, [71] -[77].

PART 5: ANALYSIS AND CONCLUSION

For all its perceived flaws, none of which this paper regards as fatal, the best interests of the child, as provided for in the Child Convention is a general interpretative principle of international law which should be taken into account in all matters concerning children. The right of a child to express his or her views has not reached such a status but remains an essential consideration in determining a child's best interests.

The Strasbourg Court's general approach to the best interests of the child in Article 8 cases cannot be described as inconsistent with the Child Convention or placing a strain on that Convention's provisions. The Strasbourg Court's approach shows an awareness of the principles of the CRC and a strong effort to take them into account. The ECHR itself does not incorporate any specific provisions concerning children and was not designed to manage children's claims.²⁶⁰ To a degree, the Strasbourg Court's approach is an example of the recognition in practice of the interdependence and interrelatedness of human rights.²⁶¹ In applying the Convention before them, a regional human rights' court cannot disregard other relevant human rights norms. In this way, the Strasbourg jurisprudence reflects an understanding of the need for children to have an independent status and occasionally require protection against their parents, a paradigm shift crystallised by the CRC.²⁶²

²⁶⁰ Fortin, above n 132, 53.

²⁶¹ The UN has declared that all human rights, including those espoused by the CRC are interdependent, indivisible, and interrelated. For an article which touches on whether this is an apt trilogy for describing human rights see: DJ Whelan, 'Untangling the Indivisibility, Interdependence, and Interrelatedness of Human Rights' Economic Working Paper Series <<http://www.econ.uconn.edu/working/7.pdf>> accessed 2 July 2009.

²⁶² Fortin, above n 132, 57.

Yet the Court cannot be lauded for offering something akin to "mutual support" to the CRC. This would require the Court to undergo a jurisprudential sea-change in two respects. First, express recognition would have to be given to the applicability of the principle of best interests in all matters involving children. Second, the principle would need to be employed at an earlier stage in the judicial analysis in defining the content and inner core of the specific Article 8 right said, by the relevant adult applicant to have been infringed. Mutual support would only be reached through a "front-end" definition of the Article 8 substantive right.

What lessons does this yield for the best interests versus benefit debate in New Zealand, which is this paper's central concern? On a specific level, the European Court of Human Rights jurisprudence does not translate cleanly into New Zealand's constitutional framework and sits awkwardly with its jurisprudential machinery. The ability of the Strasbourg Court to declare violations of rights by primary legislation is not matched by the weaker interpretative powers afforded to New Zealand judges under ss 4 to 6 of the New Zealand Bill of Rights Act 1990.²⁶³ In any event, the NZBORA contains no broad comparator to Article 8. If an Article 8 analysis is to inform the New Zealand debate, it must do so in a less direct manner. At this broader level, the preceding sketch of the European position should demonstrate four points. First, the notion of best interests has an impressive historical pedigree. Judges are familiar with it. While they may not always imbue it with the rigour this paper argues it deserves, courts have in practice managed to give meaningful recognition to the principle in difficult cases. Second, obtaining the views of the child himself or herself is an indispensable aspect of ascertaining what is in that

²⁶³ The New Zealand Bill of Rights Act 1990 ("NZBORA").

child's best interests. Third, the optimising nature of best interests and considering a child's views relative to that child's level of understanding has the capacity to sit comfortably alongside a proportionality analysis which supplies the primary machinery for human rights adjudication. Finally, an acknowledgement of children as autonomous beings and a commitment to the provisions of the CRC must surely lead, when a child's interests are brought into conflict with those of an adult or other third party, to those of the former providing the sole analytical focal point for a judge charged with resolving any conflict.

SECTION THREE: THE CONCEPT OF "BENEFIT"

This section will explore the adoption of the expression benefit in international law. It will draw on the High Court of Australian decision in *Marion's Case* to identify the distinction between best interests and benefit. The underlying question is whether, in light of the preceding discussion on the principle of best interests, the notion of "benefit" and "best interests" are synonymous and, if not, what are the material differences.

PART 1: THE USE OF BENEFIT IN INTERNATIONAL LAW

I. The Use of Benefit for Medical Procedures Generally

In international law, the requirement of free and informed consent for medical procedures is arguably universal. It is contained in all international conventions relevant to medical interventions, medical experimentation and the collection of genetic data.²⁶⁴ However, for persons unable to consent, the language defining the scope of a third party's authority to consent to a specific medical intervention is inconsistent.

The Oviedo Convention requires that if the person is unable to consent, then an intervention may only be carried out for his or her *direct* benefit. Within the Oviedo Convention itself, there are two standards of benefit: in an emergency benefit is not qualified by "direct",²⁶⁵ whereas in non-emergency situations it is.²⁶⁶ It is suggested that the time constraints implicit in emergency situations warrant a lower threshold of benefit.

²⁶⁴ See Article 5 of the Oviedo Convention, above n 7; Article 5(b) of the UDHGHR (Universal Declaration on the Human Genome and Human Rights) above n 29; Article 6 of the Universal Declaration on Bioethics and Human Rights 2005 (Adopted by UNESCO on 19 October 2005) ("UDBHR"); Article 2(iii) of the International Declaration on Human Genetic Data 2003 (Adopted by UNESCO on 16 October 2003).

²⁶⁵ Oviedo Convention, above n 7, Article 8 "Emergency Situation".

²⁶⁶ Oviedo Convention, above n 7, Article 6 "Protection of persons not able to consent".

Hence, the expression "direct" serves to make the test in non-emergency situations relatively more onerous.

The Explanatory Report to the Oviedo Convention does not elaborate on the meaning of the term "benefit".²⁶⁷ However, it does state that in agreeing on the wording of Article 6, the purpose was not to provide a single test on what amounted to a competent individual, but to protect persons unable to consent. Therefore, the Convention refers to the domestic law of the country requiring:²⁶⁸

each country to determine, in its own way, whether or not persons are capable of consenting to an intervention and taking account of the need to deprive persons of their capacity for autonomy *only where it is necessary in their best interests*.

[Emphasis added]

The inclusion of the italicised phrase has the effect of declaring that for all persons, of whom children necessarily form a constituent group, their best interests may lead to a determination that they do not have capacity and in that event what is in their direct benefit will prescribe the limits of what a person can consent to on their behalf. On this view, "best interests" and "benefit" are accorded two distinct roles. This is an unusual juxtaposition of the two concepts. The specific role afforded to "best interests" in this instrument illustrates the ease with which capacity and best interests can be collapsed into one single issue; a danger this paper has already cautioned against.²⁶⁹ Medical law is often careful to make the distinction. The standard of "best interests" is not applicable when determining whether a person is capable of consent. Rather, having established that

²⁶⁷ Council of Europe, 'Explanatory Report to the Convention on Human Rights and Biomedicine' (1996) <<http://conventions.coe.int/Treaty/EN/Reports/Html/164.htm>> accessed 2 July 2009.

²⁶⁸ *Ibid*, (accessed 2 July 2009), [42].

²⁶⁹ See Section 2, Part 4 on the child's views.

the person is not competent, it operates to define the circumstances in which the particular medical intervention can proceed.²⁷⁰ Against this background the phrase "deprivation of autonomy in one's best interests" is not a correct characterisation of how an individual's capacity is and should be determined. Rather, one must decide whether the person possesses the necessary ability to make a free and informed decision, appreciating the nature of what consent entails. If the answer is no, then one must turn to whether or not the consent of a third party should be provided on the incapable person's behalf. It is at this point that either the person's "best interests" or their "direct benefit" become relevant. The different roles accorded to the two concepts by the Oviedo Convention suggests its signatories recognised a material difference between them. Regrettably, the Explanatory Note offers no indication of what those differences were.

By contrast to the Oviedo Convention both the UDBHR²⁷¹ and the UDHGHR²⁷² limit a third party's consent by the best interests of the person concerned. The UDHGHR states that when a person is unable to consent, consent shall be obtained in accordance with the law of the country, guided by the person's best interests. Here, the expression "guided by the person's best interests", seems only to govern the obtaining of consent (and not the establishment of capacity). The UDBHR expressly acknowledges that the person who is not capable of providing consent should be involved in the decision making process.

²⁷⁰ Herring, above n 79, 161-165.

²⁷¹ Article 7.

²⁷² Article 5(b).

II. The Use of Benefit for Genetic Testing Specifically

The Genetic Testing Protocol,²⁷³ which opened for signature on the 27 November 2008 for the purposes of clarifying obligations under the Oviedo Convention with respect to genetic testing, adds an additional gloss to the direct benefit test. The Protocol provides that genetic testing can only be undertaken *for health purposes* if of direct benefit to the person tested. This suggests a dual legal regime depending on whether the test is or is not for health purposes; direct benefit if so; some unarticulated standard (if any) if not. Ascribing a broad definition to "health" would remove much of the significance of this distinction.²⁷⁴ What is meant by health is neither defined nor addressed in the Explanatory Report. Nevertheless, the World Health Organisation offers a definition of health which is very broad:²⁷⁵

Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.

If this is the operative definition, then most genetic tests could fall within it. Indeed, the Genetic Testing Protocol acknowledges that predictive testing can be carried out for health purposes and specifically envisages the following types of tests: tests predictive of a monogenic disease; tests serving to detect a genetic predisposition or genetic susceptibility to a disease; and tests serving to identify the subject as a healthy carrier of a gene responsible for a disease.²⁷⁶

²⁷³ Genetic Testing Protocol, above n 7.

²⁷⁴ If "health" were defined broadly such that all genetic testing could be deemed for health purposes, the direct benefit test would apply in every case with no content given to the category of cases to which the unarticulated criteria would apply.

²⁷⁵ World Health Organization, 'WHO Definition of Health' (<<http://www.who.int/about/definition/en/print.html>> accessed 1 July 2009.

²⁷⁶ Article 8.

The Protocol establishes an exception to the general rule in the Oviedo Convention that an intervention may only be for a person's direct benefit²⁷⁷ by providing for the possibility of "tests for the benefit of family members" in Article 13. Two points emerge from this exception. First, the mere fact that such testing is expressed as a derogation to the general rule of "direct benefit" suggests that circumstances will arise in which testing which is not of direct medical benefit to the child tested is nevertheless highly desirable. Second and relatedly, the direct benefit test comprises a more truncated inquiry than that encapsulated by a wider ranging best interests test.

Indeed, Article 13 defines the exception according to six criteria. First the purpose of the test must be to allow the family member to make an informed reproductive choice or obtain a preventive, diagnostic or therapeutic benefit that has been independently evaluated as important for their health. Second, the benefit to that family member must be solely obtainable through such a test. Third, the risk and burden of the test must be minimal for the person tested. Fourth, the expected benefit must have been "independently evaluated as substantially outweighing the risk for private life that may arise from the collection, processing or communication of the results of the test". Fifth, the person authorised to provide consent on behalf of the person unable to has done so. Finally, the person unable to consent is, in proportion with his or her capacity to understand and degree of maturity, to take part in the authorisation procedure and if s/he objects, the testing shall not proceed. Plainly, the focus of this exception is not the best interests of the child tested. Yet the breadth of the inquiry shares analogues with the best

²⁷⁷ Article 6(1) of the Oviedo Convention, above n 7. See also Article 10 of the Genetic Testing Protocol, above n 7.

interests test. Indeed, it is possible to conceive of situations in which the criteria governing the exception lead to an outcome that is in the tested child's best interests. Were direct benefit the sole test governing consent, genetic testing would be foreclosed in such cases. Three examples can be offered.²⁷⁸

*Lily is seven. She has a cancer which is thought to have a genetic basis. She is currently in remission. Lily is not competent to consent. The results of any genetic test performed on her may not change the way in which her health is managed. However, the results of the test could help diagnose other members of her family by comparing their genetic makeup with hers and the particular mutation thought to be the source of the cancer.*²⁷⁹ *If the mutation is identified in her sister or parents, they can be subject to much higher scrutiny and undergo regular tests if necessary.*²⁸⁰ *Such scrutiny could be life saving. Such a test is not to Lily's "direct benefit" since she is in remission. Lily has been explained the situation*

²⁷⁸ These are broadly drawn from the examples provided in the Explanatory Report to the Genetic Testing Protocol: see Council of Europe, 'Explanatory Report to the Additional Protocol to the Convention on Human Rights and Biomedicine, concerning Genetic Testing for Health Purposes CETS No 23' <<http://conventions.coe.int/Treaty/EN/Reports/Html/203.htm>> accessed 2 April 2009, [106]-[108].

²⁷⁹ Here the genetic test of the child is used to highlight the particular mutation in a known gene leading to the cancer. Once identified, the mutation can be used as either a pre-symptomatic or diagnostic tool for other members of Lucy's family. Regarding the former, since Lucy is manifesting the cancer as a child, one would assume incomplete penetrance: see Section 1. Therefore, other factors (e.g. environment) may result in a member of Lucy's family manifesting the disease much later despite inheriting the same mutation. In such cases, the mutation in question may be inherited in an apparent autosomal dominant manner (thus requiring only a single mutation in one gene copy). However, (and more commonly) to become symptomatic one requires "two hits" in the gene in question. This means that each copy of the gene has a mutation: one hit (mutation) is inherited, the other hit is a somatic (non-sex cell) mutation which has occurred during the person's life. An example of this type of cancer is hereditary retinoblastoma, a cancer of the retina. Here, a person inherits one mutation and develops the second mutation during his or her life time, thereby resulting in cancer. Thanks to Associate Professor Don Love of the University of Auckland Medical School, Auckland New Zealand, for his lucid explanation of how these cancers work on a genetic level and the specific example of hereditary retinoblastoma.

²⁸⁰ See the case example of the APC gene causing familial adenomatous polyposis and options for management should the mutation be discovered: A Read and D Donnai, *New Clinical Genetics* (Scion Publishing Ltd, Bloxham 2007) 316.

as fully as possible given her age, in language she can understand. She has told her parents and her doctor that she wants to be tested to "help her sister and Mummy and Daddy". In these circumstances it could be cogently argued that is in Lily's best interests to be tested: it is in line with her views; the test is non-invasive; and it may help preserve her family environment by potentially saving another member of her family.

Aldo is 10. He has been diagnosed with cystic fibrosis without reliance on a genetic test. Cystic fibrosis can be caused by many different mutations and could have been inherited by Aldo's parents or perhaps developed independently. Testing Aldo and his parents will assist his parents in establishing whether they are carriers of the mutation and have a risk of passing it on to future children, or not. Aldo has been explained the situation in language he can understand. He has been deemed not competent to consent to a test. However, Aldo has said that he is happy to be tested so that mum and dad can make a decision to have another baby. He would like a brother or sister. Testing is not to Aldo's direct or present benefit as he has already been diagnosed and his treatment plan developed. However, a test could be in his best interests: Aldo would like the test to help his family; giving effect to Aldo's views is meaningful for his autonomy and how he perceives himself as part of the family unit; the test is non-invasive; there is a small possibility that identifying the particular mutation may assist Aldo in the future (development of gene therapy).

Jessica is six years old. She is a healthy child. Her older sister has a rare genetic disorder for which the mutation has not been identified. The only current way for identifying the

disorder is by using a method called genetic linkage.²⁸¹ In order to identify a genetic mutation, genetic tests are obtained from members of the family, healthy or not. Identification of the mutation may assist in the treatment of Jessica's sister. Jessica has been found incapable of providing consent to a test. The test does not seem to be of any direct benefit to Jessica as she is currently healthy. Jessica understands that her sister is not well and understands that a test could help her. This test could be argued to be in Jessica's best interests because: she wants the test to help her sister; the test is non-invasive; the test could assist her in the future as she may in fact be a carrier of the mutation; the results could help save her sister and preserve her family unit.

PART 2: THE ADOPTION OF "THERAPEUTIC" BENEFIT AS A LIMIT ON PARENTAL POWER IN DOMESTIC LAW

At a domestic law level, the High Court of Australia has offered valuable comment on the interrelationship between best interests and benefit. In *Marion's Case*,²⁸² the High Court of Australia was faced with whether or not a parent could legally consent, without a court order, to the sterilisation of an intellectually disabled child. Two related issues arose from that central question. First, who was the repository of the power to consent on the incapable/incompetent child's behalf. Second, what legal standard governed the parameters of that consent. The majority composed of Mason CJ, Dawson, Toohey and Gaudron JJ held that the relevant limit on parental authority to consent was best interests.

²⁸¹ Linkage refers to the concept of genes being "linked" whereby loci that are close together on a chromosome tend to be inherited together. The extent of the tendency of two loci to be inherited together can be observed in a family group and used to determine the distance between the two loci measured. See more generally- Read and Donnai, above n 280, Chapter 9.

²⁸² *Marion's Case* above n 14.

However, given the special considerations pertaining to sterilisation, the majority concluded that the repository of the power to consent to sterilisation was the Court alone. They proposed three reasons for that view.²⁸³ First, sterilisation required invasive, irreversible and major surgery.²⁸⁴ Second, there was a significant risk of making the wrong decision about either the child's present or future capacity to consent or what was in the child's best interests.²⁸⁵ Third, the consequences of a wrongful authorisation of sterilisation were grave.²⁸⁶ That gravity lay in the removal of the child's reproductive ability and in the violation of one's body contrary to one's wishes or best interests. Such a violation could lead to serious social and psychological issues and impact on the child's sense of identity, social place and self-esteem. The Court were also uneasy with the far-reaching repercussions of a general rule which, in effect, permitted guardians to consent to any type of medical treatment.²⁸⁷

On analysis, the majority's approach comprised a resounding endorsement of the continued applicability of the best interests standard. Their only deviation from perceived orthodoxy lay in their requirement that the Court be the sole arbiter of best interests in certain special cases. This stemmed from an understandable concern at the only check on the parent's consent to a significant procedure being the medical practitioner performing it.

²⁸³ Ibid [48] of the majority decision.

²⁸⁴ Ibid [49] of the majority decision.

²⁸⁵ Ibid [49] of the majority decision.

²⁸⁶ Ibid [51] of the majority's decision.

²⁸⁷ Ibid [52] of the majority's decision.

However, it is the manner in which Brennan J, in dissent, responded to that same concern which is most relevant for present purposes. Taking care to confine his analysis to the sterilisation context with which the Court was solely concerned, His Honour considered the best interests test to be deficient. Fundamentally, it offered no hierarchy of values which might guide the discretionary power to authorize the medical procedure at issue.²⁸⁸ The absence of clear guidelines or rules had a number of undesirable consequences. The power to consent was reduced to an unexaminable discretion which merely reflected the subjective views of the person in whom the power to consent ultimately resided. Courts became entirely dependent upon experts supplying a dossier of fact and opinion without reference to any check-list of legal requirements. A complex moral and social question would be transformed into a question of fact.

His Honour's alternative was to replace the best interests test with a "clearer" rule based on a distinction between therapeutic and non-therapeutic interventions. Where medical treatment was for a therapeutic purpose, parental consent would be effective without Court involvement. Where medical treatment was non-therapeutic, the Court would be required to undertake a balancing act, weighing the value of the non-therapeutic purpose against the invasion of the child's personal integrity. The language of "best interests" was noticeably absent at all stages of the inquiry.

Acknowledging that there might be factual differences as to whether a procedure was therapeutic or non-therapeutic, His Honour nevertheless considered the distinction to be clear.²⁸⁹

²⁸⁸ Ibid [14] per Brennan J.

²⁸⁹ Ibid [11] per Brennan J.

I would define treatment (including surgery) as therapeutic when it is administered for the chief purpose of preventing, removing or ameliorating a cosmetic deformity, a pathological condition or a psychiatric disorder, provided the treatment is appropriate for and proportionate to the purpose for which it is administered. "Non-therapeutic" medical treatment is descriptive of treatment which is inappropriate or disproportionate having regard to the cosmetic deformity, pathological condition or psychiatric disorder for which the treatment is administered and of treatment which is administered chiefly for other purposes.

On this formulation, "therapeutic treatment" captures a particular species of medical benefit. That is seemingly confirmed by His Honour's earlier statement that therapeutic sterilisation is justified "by the need to maintain to the maximum extent or *to enhance the child's natural physical and mental attributes*".²⁹⁰ Implicit in this comment is a suggestion that each case will be self-defining by reference to a cursory determination of medical benefit. However, the inclusion of the language of proportionality in the first-quoted passage suggests that therapeutic and non-therapeutic are merely synonyms for situations where the balance of medical benefits and unarticulated costs (or harm) are respectively positive and negative. This difference in approach is more than semantic. Indeed, it reveals a critical difference between a benefit test and a best interests test.

PART 3: ANALYSIS OF THE DIFFERENCES BETWEEN *BEST INTERESTS* AND *BENEFIT*

This paper suggests that there are four main differences between a best interests test and a benefit test.

First, as has already been outlined, the qualification of "interests" by the adjective "best" implies an optimal outcome that those interests must achieve from the child's point of view. Translated into a medical context, both the procedure and the refusal of the

²⁹⁰ Ibid [20] per Brennan J [Emphasis Added.]

procedure must be considered, the detriment and benefit of each calculated, and the option which generates the greater balance of benefits over detriments undertaken. A crude benefit test requires no such optimality. That the particular test yields a (medical) benefit is, in principle, sufficient justification for a parent to provide consent, irrespective of the broader costs that procedure might engender or the superior benefits that the refusal of consent might generate.

Viewed in this way, the benefit test gives no expression to questions of balance or optimisation of the options at hand. Yet, adoption of the more balance-oriented interpretation of Brennan J's dictum (which determines whether a purpose is therapeutic or non-therapeutic), though removing one difference between best interests and benefits, highlights a second difference between the two concepts: benefit is typically equated with medical benefit. By contrast, the interests captured by a best interests test, as Eekelaar has demonstrated,²⁹¹ are not so tightly circumscribed. Physical, emotional, intellectual and autonomy interests are all potentially at play. The result is a much wider ranging inquiry than the benefit test would permit. Advocates of the benefit test, Brennan J included, cite its relative simplicity as a reason for it to be preferred. However, one must ask whether a narrower inquiry is a worthwhile price for expediency.

The normative questions raised in the preceding two paragraphs can be tested by considering two questions. First, should parents be permitted to consent to a procedure which entails no direct medical benefit to their child? Second, should parents be permitted to refuse consent to a procedure which is of direct medical benefit to the child?

²⁹¹ See Section 2, Part 2(II) for a discussion concerning the indeterminacy of the best interests principle.

As to the first point, the three examples postulated above, should be sufficient to demonstrate the harm that can be done to the child's autonomy, family dynamic and emotional state by an absolute prohibition on the provision of consent to genetic testing which would assist others while being medically neutral in respect of the child tested. In the genetic testing environment, the importance of the family unit and the psychological well being of the child and the family as a whole cannot be understated. These interests must surely be brought to bear in our analysis of whether the procedure should nevertheless be permitted.

Equally, it is possible to conceive of situations in which non-medical interests might overwhelmingly favour the refusal of consent to a procedure of medical benefit to the child. Thorny examples feature in the English case law. A child refusing a life-saving heart transplant for firmly held religious views.²⁹² Another child refusing a blood transfusion for similar reasons.²⁹³ In the genetic testing context, the presence of the APOE4 gene has been proven to demonstrate a higher risk of developing Alzheimer's disease. Taken together with the recent discovery of three new gene links to Alzheimer's,²⁹⁴ there is a real possibility that treatments directed at these specific genes could be developed in order to ameliorate the effects of Alzheimer's thereby engendering a medical benefit. Yet a child aged 12 may not wish to be tested for such genes. Knowing that their discovery indicates a strong likelihood of developing a particularly debilitating disease later in life, the child may

²⁹² *Re M (A Child) (Medical Treatment: Consent)* [1999] 2 FLR 1097 (HC) (15 year old).

²⁹³ See *Re E (A Minor) (Wardship: Medical Treatment)* above n 91 (15 year old); *Re P (medical treatment: best interests)* above n 91 (16 year old).

²⁹⁴ N Wade, 'Three Genetic Variants Are Found to be Linked to Alzheimer's' *The New York Times* (New York 7 September 2009) A4.

wish to remain ignorant of her fate, irrespective of any attendant medical benefits that early intervention may generate. We might legitimately differ on whether consent should be granted or withheld in such circumstances. Yet a benefit test precludes this debate from ever occurring. Rather, medical benefit is arbitrarily declared to be the sole principle around which parental consent is calibrated.

Third, aside of the use of the adjective "best", there is an additional linguistic difference in the use of "interests" versus "benefit". The Oxford dictionary defines "interest" as "the advantage or benefit of a person or group".²⁹⁵ Plainly interest and benefit are capable of amounting to the same thing. Yet there is a meaningful difference between the two. Talk of "interests" as opposed to "benefits" engages an entire language of rights. A language which instantly evokes the notion of dignity and accords more closely with the child as autonomous being and right-bearer.

The final difference lies in the procedural nature of each test. Best interests and benefit affect more than the substantive outcome. Procedurally, they comprise different means of involving children in the decision making process. Benefit absolutely forecloses any consideration of a child's views: s/he plays no role in the ultimate outcome as there is no reason for those views to be obtained. Best interests, by contrast, reverses both of these conclusions: a child's autonomy is a relevant factor to be thrown into the analytical mix; his/her views must accordingly be sought. The notion of balance and proportionality which best interests automatically captures provides an ideal vehicle through which

²⁹⁵ Soanes and Stevenson (eds), above n 125.

involvement in the decision making process relative to a child's understanding can be adequately reconciled.

This paper has already argued that the criticisms levelled at best interests are overstated. Moreover, those who advance such criticisms fail to offer a superior alternative in its place. Consideration of the "benefit" standard demonstrates that it is just as vulnerable to a charge of opacity as the best interests test. While we have seen that "benefit" has been limited to medical benefit there is no logical reason why this should be so. Indeed, the report of the HGRP suggests "benefit" to be a concept capable of transcending overt clinical benefit.²⁹⁶ One might inquire whether such a broad a view of benefit is simply best interests under another name. If this were to be so, incompetent children could be subjected to significant medical procedures based on a vague notion of "benefit" without the attendant safeguards that a best interest test involves: a consideration of detriment; the requirement for optimality; engaging the child in the process; and the familiar rights tradition best interests engages with. The normative justification for such an approach is unclear. Consent to a procedure demonstrated and accepted to be in the child's best interests is self-justifying. Consent to a procedure established to merely generate a *benefit* is less so.

Concerns at the opacity of "best interests" can be met by requiring courts who are the ultimate arbiters of that question to substantiate their conclusion and articulate their reasoning as fully and transparently as possible. The response might be that in practice, few cases ever go to court. Central to the HGRP's recommendation for the adoption of "benefit" is the absence of practical legal interventions to prevent parents from making

²⁹⁶ HGRP, above n 4, 274.

medical decisions which are not in their child's best interests. This concern gains little traction when dealing specifically with genetic testing. The requirement for genetic counselling prior to the undertaking of a genetic test ensures that a greater number of objective "outsiders" are aware and involved in the decision making process prior to the test taking place. There is a greater likelihood of court assistance being sought to determine the overriding legal issue. As the following section will demonstrate, a best interests test is more likely to uphold the child's dignity in such situations.

SECTION FOUR: THE DIGNITY OF THE CHILD

Dignity is trendy. In the area of bioethics, it has consistently attracted much legal scholarship.²⁹⁷ It is heavily relied on in international politics and has been showered more attention in recent times by philosophers and political theorists.²⁹⁸ It is said to be a common thread which underpins the fundamental values of democracy, citizenship and participation.²⁹⁹ However, there seems to be little evidence that such attention has had much, if any, effect on the legal and judicial meanings afforded to the concept.³⁰⁰ This is particularly evident in New Zealand where dignity is seldom relied on in any substantive capacity. When it comes to international human rights law, dignity is ubiquitous and as a concept, is notoriously hard to pin down. Some authors adopt it as *the* foundational concept of all human rights, that sacred elixir upon which all human rights are weaned. Others, adopt dignity as an interpretative principle of human rights law. A further account views dignity as a right in itself.

The aim of this last section is to examine, in light of a framework for the meaning and uses of dignity, how dignity has been judicially interpreted in the context of children's rights and how it may inform the debate about the question at the heart of this paper, namely whether

²⁹⁷ For more recent publications see: Bioethics Council, *Human Dignity and Bioethics* (President Council on Bioethics, Washington DC 2008); D Beylveid and R Brownsword, *Human Dignity in Bioethics and Biolaw* (Oxford University Press, Oxford 2001).

²⁹⁸ C McCrudden, 'Human dignity and judicial interpretation of human rights' (2008) 19 *The European Journal of International Law* 655, 663.

²⁹⁹ D Oliver, 'The Underlying Values of Public and Private Law' in M Taggart (ed) *The Province of Administrative Law* (Hart Publishing, Oxford 1997) 217.

³⁰⁰ McCrudden, above n 298, 663.

the child's best interests or the child's benefit should operate as a limitation on parental authority to consent to a genetic test on behalf of the child.

PART 1: HISTORICAL CONCEPTS OF DIGNITY

There are many and overlapping meanings of dignity. In Roman thought, dignity was equated to status: one's status carried with it varying degrees of honour and respect.³⁰¹ In this sense, the term evoked a person's worthiness.³⁰² Also present during this period, but less prominent, was a conception of dignity as that which the human acquired by virtue of being human (with no additional status), in contrast with being an animal.³⁰³ Such a concept of dignity begged the question of the exact boundaries of the *human*. As one scholar points out "[r]adically different answers are possible, of course, and therein lies the root of the problem with the concept of dignity".³⁰⁴ Answers to these questions can be furnished from three sources: religion, which links the answers to the supernatural; philosophy which employs philosophical rigour; and history which examines the types of actions that have historically been considered violations of dignity.³⁰⁵ Religious thought shaped the idea of dignity as "dignity inherent in Man". Man being made in the image of God was "endowed with gifts" which rendered him distinct from animals.³⁰⁶ Giovanni

³⁰¹ D Chalmers and R Ida, 'On the International Legal Aspects of Human Dignity' in J Malpas and N Lickis (eds), *Perspectives on Human Dignity: A Conversation* (Springer, Dordrecht 2007) Professor Waldron has also examined this notion of dignity as "status" or "rank": J Waldron, 'Dignity and Rank' (2007) 48 *Archives Européennes de Sociologie* 201; J Waldron, 'How Law Protects Dignity' (Paper presented at the European University Institute, Florence 27 January 2009) .

³⁰² McCrudden, above n 298, 657.

³⁰³ *Ibid*, 657.

³⁰⁴ *Ibid*, 657.

³⁰⁵ *Ibid*, 658.

³⁰⁶ *Ibid*, 659.

Pico della Mirandola's *Oratio De Hominis Dignitate* (Discourse on the Dignity of Man) in 1486 emphasised the link between dignity and the capacity for choice.³⁰⁷ The treatise, composed of 900 *conclusiones*, disagreed with previous scholars that what set Man apart from other beings was a rational power or domination over animals.³⁰⁸ Rather, Pico argued that Man had dignity because He had no predetermined nature and could choose His desired from of existence.³⁰⁹ His work, considered to be the manifesto of the Renaissance,³¹⁰ emphasised humans' ability to use reason, an ability divorced from office and hierarchy.³¹¹ Such an ability served the purpose of overcoming religious differences. With time, dignity's ties with religion were consciously dissolved in favour of "the central existential claim of modernity - man's autonomy, his capacity to be the lord of his fate and the shaper of his future".³¹² Kant relied on this conception of dignity upon which to build

³⁰⁷ Pico della Mirandola settled in Florence in 1484 at the age of 21 and wrote *Oratio De Hominis Dignitate* at the Badia Fiesolana, the current location of the European University Institute. His work is said to essentially define "the aspirations and self-understanding of Renaissance humanism". A "precocious" and "spectacular" individual, he was a close friend of Lorenzo (The Magnificent) de' Medici. Some 13 of Pico's 900 theses were considered heretical by the papal authorities and Pico was arrested in 1488. Lorenzo intervened on Pico's behalf and Pico was permitted to return to Florence. He settled in Fiesole until Lorenzo's death in 1492 when he moved to Ferrara. He died under suspicious circumstances in 1494 at the age of 31 (he is said to have been poisoned). See generally: P Strathern, *The Medici: Godfathers of the Renaissance* (Pimlico, London 2005).

³⁰⁸ I Englard, 'Human Dignity: From Antiquity to Modern Israel's Constitutional Framework' (1999-2000) 21 *Cardozo Law Review* 1903, 1914.

³⁰⁹ There is disagreement over the foundation and meaning of Pico's notion of dignity. Some suggest that it simply embodied the traditional medieval religious views, others argue that it promoted a move towards secular tendencies. See: O Boulnois, 'La Dignité de l'Image, ou l'Humanisme Est-Il Métaphysique?' in P Magnard (ed) *La Dignité de l'Homme* (Librairie Honoré Champion, Paris 1995).

³¹⁰ Brown University, 'Progetto Pico / Pico Project' (2009) <http://www.brown.edu/Departments/Italian_Studies/pico/> accessed 2 September 2009.

³¹¹ McCrudden, above n 298, 659.

³¹² Y Arieli, 'On the Necessary and Sufficient Conditions for the Emergence of the Dignity of Man and His Rights' in D Kretzmer and E Klein (eds), *The Concept of Human Dignity in Human Rights Discourse* (Kluwer Law International, The Hague 2002) 12.

his own theory, a theory whose exact meaning continues to be contested.³¹³ Kant's use of the term dignity is generally accepted to mean two things: that persons are ends in themselves and may never be treated as means to an end; and that dignity requires treating persons as autonomous and capable of making their own choices.³¹⁴

PART 2: USE OF DIGNITY IN THE LEGAL SYSTEM

I. Core Meaning and Role

Three useful analyses illuminate the modern meaning of dignity, how dignity is relied on and the role it may play. First, McCrudden proffers a minimum core of dignity comprising three elements: every human possesses an intrinsic worth; this intrinsic worth should be recognised and respected by others; and recognition of intrinsic worth requires that the state should exist for the sake of the individual and not vice versa.³¹⁵ This minimum core defines the bare meaning of the term dignity itself. McCrudden argues that judicial discourse reveals no consensus as to the meaning of dignity beyond these parameters.³¹⁶

Second, Clapham recognises four different aspects of dignity.³¹⁷ It is submitted that these aspects are best understood as "manifestations" of dignity; the usual scenarios where

³¹³ McCrudden, above n 298, 659.

³¹⁴ *Ibid*, 659-660; Chalmers and Ida, above n 301, 160.

³¹⁵ McCrudden, above n 298, 679.

³¹⁶ *Ibid*, 710-712.

³¹⁷ A Clapham, *Human Rights Obligations of Non-State Actors* (Oxford University Press, Oxford 2006) 545-546.

dignity, howsoever defined, is perceived as important and given effect (be it in a domestic statute, a court case or an international instrument):³¹⁸

(1) the prohibition of all types of inhuman treatment, humiliation, or degradation by one person over another; (2) the assurance of the possibility for individual choice and the conditions for 'each individual's self-fulfillment', autonomy, or self-realization; (3) the recognition that the protection of group identity and culture may be essential for the protection of personal dignity; (4) the creation of the necessary conditions for each individual to have their essential needs satisfied.

Finally, writing primarily from a bioethics standpoint, Brownsword and Beyleveld see dignity as featuring in two ways within society. First, there is dignity as a virtue or "dignified conduct".³¹⁹ This is the modern expression of equating dignity to one's status or rank within society. *Dignified conduct* as a character virtue stems from a person's attitude towards adversity.³²⁰ Dignity as a virtue operates in tandem with the second kind of dignity: human dignity as inherent worth. Dignity as inherent worth can be viewed from the perspective of the individual or that of the community.³²¹ Potentially, within either perspective, dignity can then fulfill two roles: dignity as empowerment or dignity as constraint.³²² In practice dignity as empowerment tends to be individual-focussed and dignity as constraint community-focussed.³²³ Brownsword and Beyleveld explicitly favour

³¹⁸ Ibid 545-546.

³¹⁹ Beyleveld and Brownsword, *Human Dignity in Bioethics and Biolaw* above n 297, 58.

³²⁰ Ibid 59.

³²¹ Ibid 64.

³²² R Brownsword, 'Human Dignity, Ethical Pluralism, and the Regulation of Modern Biotechnologies' in T Murphy (ed) *New Technologies and Human Rights* (Oxford University Press, Oxford 2009); Beyleveld and Brownsword, *Human Dignity in Bioethics and Biolaw* above n 297, 26; R Brownsword, 'Genomic Torts: An Interest in Human Dignity as the Basis for Genomic Torts' (2003) 42 *Washburn Law Journal* 413, 419-422.

³²³ Beyleveld and Brownsword, *Human Dignity in Bioethics and Biolaw* above n 297, 64.

dignity as empowerment.³²⁴ McCrudden characterises these contrasting approaches as dignity as an expression of individual liberty and autonomy and dignity as an expression of communitarian values.³²⁵ McCrudden does not perceive these two roles as informing the content of the meaning of dignity. Rather, they are two different ways of rationalising dignity's use in any given case.

In Brownsword's view, dignity conceived as empowerment is closely linked with modern human rights.³²⁶ Here, dignity is about inherent worth as a human being which encompasses the capacity to make choice. Accepting that respect for this type of dignity and capacity for choice should be recognised supports three universal claims enjoyed by every person: recognition of one's capacity to choose; respect for freely made choices; and appreciation of the need for a supportive context for autonomous-decision making.³²⁷

Brownsword argues that human dignity as constraint "lacks a clear and unifying anchoring point".³²⁸ The so-called *dignitarian alliance*³²⁹ relies on this type of dignity to justify constraining individual rights. Dignity encompassing communitarian values can (and

³²⁴ Brownsword, 'Human Dignity, Ethical Pluralism, and the Regulation of Modern Biotechnologies' above n 319; Beyleveld and Brownsword, *Human Dignity in Bioethics and Biolaw* above n 297, 26; Brownsword, 'Genomic Torts' above n 322, 419-422.

³²⁵ McCrudden, above n 298, 699.

³²⁶ Brownsword, 'Human Dignity, Ethical Pluralism, and the Regulation of Modern Biotechnologies', above n 322, 26-29.

³²⁷ Ibid 27.

³²⁸ Brownsword, 'Genomic Torts' above n 322, 420.

³²⁹ The dignitarian alliance claim that human dignity must not be compromised and that the duty to respect dignity is fundamental. If an action is deemed to be unethical by being contrary to human dignity, it will not stand regardless of a person's informed consent. It is an *alliance* because there is more than one pathway or justification for this claim: Kantian, communitarian or religious: Beyleveld and Brownsword, *Consent in the law* above n 33, 31-32.

tends to) operate as a restraint on the right in question.³³⁰ Although it is possible for a concept of human dignity which focusses on what is "special about a particular community's idea of a civilised life and the concomitant commitment of its members" to support human dignity as empowerment,³³¹ in practice this does not occur.³³²

As we saw in the first section concerning the competence to consent, Beyleveld and Brownsword adopt Gewirth's moral theory of agents.³³³ One will recall that this theory proposes that every agent operates within the overarching principle of equal and universal human rights, also called the Principle of Generic Consistency (PGC) (a principle of morality). Within this theory, agents have reciprocal rights and duties to respect one another's freedom and well-being. Interpreting dignity as intrinsic worth and as dignified conduct permits the authors to draw some conclusions about the appropriateness of the communitarian role that dignity can play. In terms of intrinsic worth, whether or not Agent A's dignity has been compromised by *other* agents requires consideration of whether A 'freely' invites the compromising conduct; not whether A, according to an external

³³⁰ In *Wackenheim v France* above n 44, the HRC held that a prohibition of dwarf throwing was justified on the basis of human dignity, the protection of which was essential for *ordre public*. Mr Wackenheim relied on human dignity as empowerment, submitting that he was choosing this employment and therefore not being treated as a mere thing.

³³¹ Brownsword, 'Human Dignity, Ethical Pluralism, and the Regulation of Modern Biotechnologies', above n 322, 30.

³³² *Ibid* 30. The employment of dignity in this manner should be viewed with caution. Stretched to its logical conclusion it can support a consequential and majoritarian approach to the determination of individual rights - the very antithesis of human rights.

³³³ The Gewirth model requires that rights be understood according to the will (or choice) theory of rights, potentially creating difficulties when it comes to accommodation children. See above n 37.

observer has lost self-respect as a result of the conduct.³³⁴ If the loss of self-respect was freely invited, respect for dignity requires that there be no interference in the conduct. Any interference would be treating the agents as mere things and breach their dignity. For Gewirth, agent A's right of autonomy is fundamental. Therefore, A's *own* dignity (intrinsic worth) will not be compromised if no harm is done to the PGC-protected rights of other agents. In terms of dignity as "dignified conduct", if dignified conduct by A would indirectly promote respect for the PGC rights of other agents, then it is a virtue which other agents are entitled to have A cultivate.³³⁵

At this point, we have explored the bare scope of dignity and four scenarios where dignity tends to arise. Creating a further layer of complexity is the two, usually conflicting, roles that dignity may fulfil: empowerment and constraint. The next question is how dignity is actually understood and used within judicial reasoning.

II. Judicial Reliance on Dignity

McCrudden elaborates two central judicial understandings of dignity.³³⁶ First, a court may understand dignity as providing a basis for human rights in general. This answers questions such as why human persons should have rights at all and what the scope of those rights

³³⁴ D Beyleveld and R Brownsword, 'Human Dignity, Human Rights, and Human Genetics' in R Brownsword, WR Cornish and M Llewelyn (eds), *Law and Human Genetics: Regulating a Revolution* (Hart Publishing, Oxford 1998) 79. The determination of a loss of self-respect (each individual's self-esteem being central) is key to Kantian dignity. Loss of self-respect is relied on by the *dignitarian alliance* as an *objective* measure with a communitarian agenda.

³³⁵ *Ibid* 81.

³³⁶ McCrudden, above n 298, 680.

should be.³³⁷ Within this there are "thin" and "thick" approaches. The thin approach perceives dignity as a way of expressing a catalogue of human rights but does not add to or detract from their substance. The thick (and more common) view perceives dignity as being a value unique to itself, distinct from the human rights which it created. Here, dignity is relied on as a general principle to identify those rights within the human rights catalogue worth protecting. On this view, dignity justifies the existence of human rights, can be a general principle assisting in creating and defining rights and can also be an interpretative principle where rights "come to be seen as best interpreted through the lens of dignity".³³⁸ Second, courts understand dignity as a right or an obligation in itself with specific content. Here, dignity can be either an enforceable right or a principle which exists behind other rights but is not of itself enforceable.³³⁹

Regardless of a judge's understanding of dignity, s/he may in fact draw on the use of dignity in other foreign jurisdictions.³⁴⁰ Each jurisdiction affords dignity a different weight and status,³⁴¹ and takes a different stance on the role that dignity should play (empowerment versus constraint). This in turn affects the perspective adopted in a particular case (subjective/individual or objective/court-centred) and whether dignity can be waived.³⁴²

³³⁷ One scholar who subscribes to the view that human dignity is the foundation of human rights law is Federico Lenzerini. See: F Lenzerini, 'Biotechnology, Human Dignity and the Human Genome' in F Francioni and T Scovazzi (eds), *Biotechnology and International Law* (Hart Publishing, Oxford 2006)

³³⁸ McCrudden, above n 298, 681.

³³⁹ *Ibid*, 681.

³⁴⁰ *Ibid*, 694.

³⁴¹ *Ibid*, 699.

³⁴² *Ibid*, 706. As to waiver, in some jurisdictions dignity is seen as fulfilling a predominantly communitarian function and may not be waived by the individual.

McCrudden submits that dignity may be more adept at resolving certain institutional difficulties. Dignity could be relied on to resolve "conflicts of rights, and conflicts between rights and other values"; to establish "how far the rights which are to be interpreted should be seen as instantiating international standards";³⁴³ to determine "how far the text of the national (or regional or international) Bill of Rights should be seen as determinative, and how to react when the text appears not to support a strong judicial desire to intervene".³⁴⁴

III. The International Legal System

Dignity is either expressly or implicitly imported into every international instrument of relevance to the field of human genetics and human rights. The concept of dignity has been hailed as "one of the most important, innovative elements introduced into International Law".³⁴⁵ Since 1986, the UN General Assembly has provided in its guidelines for new human rights instruments that they should be "of fundamental character and derive from the inherent dignity and worth of the human person".³⁴⁶ One writer states that those rights which are fundamental to the protection of human dignity, of universally accepted values of humanity and whose violation results in condemnation from the international community require less confirmatory evidence than other customary rights.³⁴⁷

³⁴³ Here dignity "allows each jurisdiction to develop its own practice of human rights" by enabling (and requiring) judges to incorporate their domestic context in the interpretation of human rights norms: *Ibid*, 714.

³⁴⁴ *Ibid*, 714.

³⁴⁵ K Dicke, 'The Founding Function of Human Dignity in the Universal Declaration of Human Rights' in D Kretzmer and E Klein (eds), *The Concept of Human Dignity in Human Rights Discourse* (Kluwer Law International, The Hague 2002) 111.

³⁴⁶ McCrudden, above n 298, 669.

³⁴⁷ T Meron, *Human Rights and Humanitarian Norms as Customary Law* (Oxford University Press, Oxford 1989) 94.

The founding Charter of the United Nations relies on the concept of dignity in its Preamble. Subsequently, the Preamble to each of the "International Bill of Rights", the Universal Declaration of Human Rights 1948 ("UDHR"), the International Covenant on Economic, Social and Cultural Rights 1966,³⁴⁸ and the ICCPR³⁴⁹ refer to dignity. Dignity's particular prominence in the UDHR is frequently relied on to argue that human rights were politically and legally founded on human dignity.³⁵⁰ The Preamble to the Child Convention³⁵¹ links the expression "dignity" to that adopted in the UDHR thereby emphasising the child's dignity.

In that vast area where science and human persons collide, international law has been particularly active. The central aim of the Oviedo Convention³⁵² is to protect "the dignity and identity of all human beings and guarantee everyone, without discrimination, respect for their integrity and other rights and fundamental freedoms with regard to the application of biology and medicine". It is clear that "human dignity ... constitutes the essential value to be upheld ... [and] is at the basis of most of the values emphasised in the [Oviedo] Convention".³⁵³ The Genetic Testing Protocol³⁵⁴ also provides for the protection of dignity and identity of all human beings.³⁵⁵

³⁴⁸ International Covenant on Economic, Social and Cultural Rights 1966, opened for signature on 16 December 1966 (entered into force 3 January 1976).

³⁴⁹ Above n 130.

³⁵⁰ Dicke, above n 345, 111.

³⁵¹ The Child Convention above n 5.

³⁵² The Oviedo Convention, above n 7.

³⁵³ Council of Europe, Explanatory Report to the Oviedo Convention, above n 267, [9].

³⁵⁴ Genetic Testing Protocol, above n 7.

³⁵⁵ Article 1.

The UDHGHR³⁵⁶ is concerned with the protection of human dignity with regard to current and future research on the human genome. It proclaims that the human genome underlies the recognition of the inherent dignity of all members of the human family.³⁵⁷ It reminds us that regardless of genetic characteristics, each person has a right to respect for their dignity³⁵⁸ and bans any practices which are contrary thereto.³⁵⁹

The UDBHR³⁶⁰ has neither legal force nor a mechanism for enforcement. It faced criticism in bioethics circles on numerous grounds, notably its reliance on problematic concepts such as human dignity.³⁶¹ The central aim of the UDBHR was to identify those bioethical principles which were universally acceptable and in conformity with international human rights law.³⁶² Indeed, the UDBHR "anchors the principles it endorses in the rules that govern respect for human dignity, human rights, and fundamental freedoms".³⁶³ The UDBHR expressly recalls the Child Convention in its preamble. The three key concepts of "human dignity, human rights and fundamental freedoms" are reaffirmed throughout the UDBHR. Their promotion is an explicit aim of the UDBHR;³⁶⁴ their respect is

³⁵⁶ Above n 29.

³⁵⁷ Article 1.

³⁵⁸ Article 2.

³⁵⁹ Article 11.

³⁶⁰ Above n 264.

³⁶¹ R Ashcroft, 'The Troubled Relationship Between Bioethics and Human Rights' in M Freeman (ed) *Law and Bioethics* (Current Legal Issues, Oxford University Press, Oxford 2008) 37.

³⁶² H ten Have, 'The Activities of UNESCO in the Area of Ethics' (2006) 16 *Kennedy Institute of Ethics Journal* 333, 341.

³⁶³ *Ibid*, 341.

³⁶⁴ Article 2(c).

commanded³⁶⁵ and all advances in science and technology must be consistent with them.³⁶⁶ Moreover, human beings are recognised as equal in rights and in dignity.³⁶⁷ The UDHR separately recognises respect for autonomy³⁶⁸ and respect for human vulnerability and personal integrity.³⁶⁹

Lenzerini argues that the cumulative effect of the above provisions, (combined with the international legal climate in the area of biogenetics)³⁷⁰ is that the dignity of the individual prevails "over both the general interest to research and scientific progress ... and any other interest of society as a whole".³⁷¹ This, he submits, is consistent with the "very nature" of international law; respect for human dignity being the *raison d'être* of human rights law.³⁷²

Dignity is noticeably absent in the European Convention, the first binding international treaty to follow the UDHR. However, the ECHR's provisions have always been consistently interpreted with the concept of dignity and now the Strasbourg Court regards human dignity as underpinning all of the European Convention rights.³⁷³

³⁶⁵ Article 3.

³⁶⁶ Article 2(d).

³⁶⁷ Article 10.

³⁶⁸ Article 5.

³⁶⁹ Article 8.

³⁷⁰ See e.g. United Nations Declaration on Human Cloning (Adopted by United Nations on 8 March 2005).

³⁷¹ Lenzerini, above n 337, 336.

³⁷² *Ibid.*

³⁷³ *Pretty v United Kingdom* (1997) 35 EHRR 1 (ECtHR), at [65].

IV. The New Zealand Legal System

New Zealand judges do rely on the concept of dignity, but reliance is patchy and typically confined to certain areas. There is a dearth of case law addressing the meaning of dignity in any detail. Human dignity has been referred to as "a dominant theme in civilised life".³⁷⁴ While discussing the legitimacy of the common law and its necessary development to reflect the ongoing and significant advances in medical knowledge and skills, Baragwanath J commented that:³⁷⁵

... the litmus test for any law is the dignity of the individual, recognised by art. 1 of the Universal Declaration of Human Rights and underlying the provision of rights to health consumers by the Health and Disability Commissioner Act 1994 and the Code of Health and Disability Services Consumer Rights ...

Leaving aside those national statutes which recognise or give effect to international instruments containing the term dignity,³⁷⁶ in New Zealand there are three broad categories of provisions in which dignity is mentioned.³⁷⁷ First, dignity operates as a limitation on the exercise of state power. Statutes which grant search powers generally provide that any search is to be carried out in accordance with the dignity of the individual being searched.³⁷⁸ Moreover, every person who is detained or arrested has the right to be treated with humanity and with respect for the inherent dignity of the person.³⁷⁹ Indeed,

³⁷⁴ *Director of Proceedings v Nursing Council of New Zealand* [1999] 3 NZLR 360 (HC).

³⁷⁵ *Patient A v Health Board X* HC BL CIV-2003-406-14, 15 March 2005, Baragwanath J (HC) at [65].

³⁷⁶ E.g. Children Commissioner's Act 2003 where one of the purposes is to give better effect to the CRC in New Zealand.

³⁷⁷ These closely follow the manifestations of dignity described by Clapham. See above n 317.

³⁷⁸ Financial Transactions Reporting Act 1996; Corrections Act 2004; Penal Institutions Act 1954; Children Young Persons and Their Families Act 1989; Misuse of Drugs Act 1978.

³⁷⁹ NZBORA, above n 263, s 23.

humane treatment is the touchstone of the meaning of dignity within s 23(5) of the NZBORA.³⁸⁰

Second, numerous remedial provisions recognise loss of dignity, humiliation and injury to feelings as a head of damages.³⁸¹ The positive obligation which this head of damages enforces is that, in certain situations, a person is to be treated with dignity and with due regard for his/her feelings. Treating persons with dignity in, for example, their employment provides the conditions necessary for self-fulfilment, autonomy and self-realisation. Third, there are those provisions which require that certain services are to be provided or certain duties are to be performed with respect for dignity.³⁸² Dignity is often linked with "independence" or "autonomy". There are two specific examples relevant to the genetic testing of children. The HADCA (and its accompanying Code) provides that all duties are to be provided in a manner which respect the *dignity and independence* of the individual. Although dignity underlies the Health and Disability Commissioner Act,³⁸³ it is seldom relied on, except insofar as s 57(1)(c) is concerned, which recognises that damages may be awarded for breaches of the Code resulting in humiliation, loss of dignity and injury to feelings. The other example is the Human Tissue Act 2008 which applies to the collection of a genetic sample. That Act ensures the collection and use of human tissue is done with

³⁸⁰ *Taunoa v The Attorney-General* [2008] 1 NZLR 429 (SC) at [79] per Elias CJ.

³⁸¹ Employment Relations Act 2000; Human Rights Act 1993; Police Act 1958; Labour Relations Act 1987; Human Rights Commission Act 1977 (for claims between 1984 and 1992); Health and Disability Commissioner Act 1994; Privacy Act 1993. As to the latter Act, if an action results in significant humiliation, significant loss of dignity or significant injury to feelings, that can help make out an interference with privacy justifying compensation.

³⁸² Human Assisted Reproduction Technology Act 2004; Human Tissue Act 2008; Health and Disability Commissioner Act 1994; Victims' Rights Act 2002.

³⁸³ *Patient A v Health Board X* above n 375.

the proper recognition and respect for the *autonomy and dignity* of the individual whose tissue is collected or used. It has yet to be relied on in New Zealand.

There has been no case in which dignity has been substantively relied on in the context of any failure to provide a service towards or any failure to perform an obligation owed to a child.³⁸⁴ Moreover, no case has ever substantively explored the meaning of dignity in the context of children's rights, although it is accepted that every child has his or her own dignity, independent of his or her parents.³⁸⁵ The acceptance of such a fact represents a transformation of the "traditional" parent-child relationship from one of dependence to one of independence and is said to have occurred through the increased reliance on certain common values in the legal system, including dignity, autonomy and respect.³⁸⁶ Overall, this transformation represents a democratisation of the parent-child relationship and decision making.³⁸⁷

³⁸⁴ I am excluding from this statement criminal law cases involving offences against children. To date there have only been three New Zealand cases which have mentioned dignity in the context of children's rights: *AD v KT [Parenting Order]* [2008] NZFLR 761 (HC); *Ausage v Ausage* [1998] NZFLR 72 (FC) and *TV3 v R HC AK CRI-2005-092-14652*, 7 July 2006, Winkelmann J (HC). None of these cases is relevant for present purposes.

³⁸⁵ *Ye v Minister of Immigration* [2008] NZCA 291 (CA) at [129] quoting Sachs J in the decision of *M v The State* [2007] ZACC 18 (Constitutional Court of South Africa) at [18]. The notion of the dignity of the child has been relied on in other immigration cases, but again, the meaning or scope of dignity is not explored: *Ding v Minister of Immigration* (2006) 25 FRNZ 568 (HC).

³⁸⁶ Oliver, above n 299, 234. Although note here that Oliver understands dignity in a narrow sense to mean honour and reputableness: *Ibid* 225.

³⁸⁷ *Ibid* 236.

And what of terms which are often associated with dignity, such as inviolability, bodily integrity and autonomy? In New Zealand, while the autonomy of the child is accepted,³⁸⁸ no available case has explored its scope in any detail. Although autonomy was not employed, the High Court decision of *Hawthorne v Cox* recognised a presumption of a child's ability to make his or her own decisions upon reaching the age of 16.³⁸⁹ The term *independence* is sometimes relied on to express the child's independence within the family unit and recognition of that child as an individual distinct from other members of the family.³⁹⁰ A recognition of a child's independence or a child's decision making capacity are closely related to a recognition of *autonomy* and in turn *dignity*. However, by not relying on the term dignity when resolving legal conflicts involving children, core values which it stands for can be lost, in particular the inherent worth of the child.

PART 3: APPLICATION OF THE CONCEPT OF DIGNITY TO THE RESEARCH QUESTION

Dignity cannot be ignored. It supplies the essence of humanity. We have seen that the international legal community has promulgated countless instruments which express dignity as a fundamental principle. Those same instruments acknowledge that that importance is not altered when medical and scientific advances are at play. At a domestic

³⁸⁸ Usually child autonomy is considered in child abduction cases, when examining the underlying rationale for Article 13 of the Convention on the Civil Aspects of International Child Abduction which permits the abductor to raise as a defence the fact that the child objects to being returned. See for example *W v N* [2006] NZFLR 793 (HC). See also *Hollins v Crozier* [2000] NZFLR 775 (DC), where Doogue J at 797 noted that Article 12 was the linchpin of the Child Convention in its recognition of the child's personality and autonomy.

³⁸⁹ *Hawthorne*, above n 62, [71].

³⁹⁰ *Hinaki v Bateman* [2001] NZFLR 548 (FC); *F v F* [FAM-2004-002-186] 24 August 2006, Judge O'Dwyer (FC).

level, the legal significance of dignity is less expressly declared but its force is no less pervasive. Case law implicitly embodies it. Statute expressly endorses it. For these reasons, dignity must certainly feature in any analysis of the parameters of a guardian's consent on behalf of an incompetent child.

How does dignity answer the overarching question within this section? In *Marion's Case*³⁹¹ a divided High Court of Australia furnished two competing answers. The Court unanimously recognised that consent was closely connected to the right of bodily integrity and inviolability.³⁹² For its part, the majority (joined by McHugh J) held that the best interests of the child was the key overarching limit on parental power,³⁹³ a limit which best protected a child's dignity for non-special procedures.³⁹⁴ For his part, Brennan J limited parental authority by reference to a therapeutic benefit best as best protecting the child's dignity.

Four differences have been elaborated upon in the preceding sections. Of those, three are particularly pertinent to the dignity of the child: that best interests imports the language of interests; enables the views of the child to be taken into account; and takes into account a broader range of factors. Indeed, these three aspects of the best interests test are what will enable children's rights to feature in genetic testing decision making. On Brownsword and Beyleveld's view, a children's rights-focussed approach to genetic testing requires that

³⁹¹ *Marion's Case* above n 14.

³⁹² *Ibid* at [10] of the majority decision; at [3] of McHugh J's decision.

³⁹³ *Ibid* at [26]-[27] of the majority's decision. At [16] of of McHugh J's decision.

³⁹⁴ As we have seen, the majority created a legal test whereby special procedures could be singled out for court order.

dignity, *as far as possible*, fulfil an empowerment function.³⁹⁵ The instability of the communitarian dynamic with which dignity as constraint is typically associated has been shown to provide too unstable a platform for the existence of human rights. Moreover, dignity as empowerment is consistent with numerous provisions in the CRC: respect for the evolving capacities of the child; obtaining the child's views; and recognition of a child as an independent person, separate from his or her family. New Zealand, as is evidenced by the case law, takes such an approach.³⁹⁶

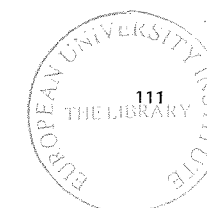
Admittedly, when children are involved, there are theoretical difficulties in adopting Gewirth's moral theory of rights. Gewirth's agents require the capacity to make free decisions and possess a will. In Gewirth's model, children who lack competence are at best proto-agents (with future capacity) as they are not yet able to make a free decision backed by a purpose. Yet this does not mean that the child ceases to become a human entitled to dignity. The binary nature of capacity which sees a child as either not competent or competent can conceal this fact. A finding of incompetence or incapacity does not mean that the child is incapable of understanding anything, has no idea what is going on or is incompetent to make *any* decision. As Raz acknowledges, the fully autonomous person is a fiction. For this reason, the conclusion that the protection of the relevant child's dignity must be transferred to the person making the decision on their behalf, namely the parent, must be handled with care. This "transfer", for want of a better word, should not compel the exclusion of the child from the equation. There is no reason

³⁹⁵ Beylvelde and Brownsword, 'Human Dignity, Human Rights, and Human Genetics' above n 334; Brownsword, 'Human Dignity, Ethical Pluralism, and the Regulation of Modern Biotechnologies' above n 322.

³⁹⁶ See Section 2, Part 4 (III) on New Zealand's approach to the child's views.

why forfeiture of the ability to consent to a particular action should be accompanied by the surrender of further aspects of dignity: the ability to have one's views considered; the ability to have the surrogate decision-maker consider all factors the child, if competent, would take into account before making a decision directly affecting him/herself; and most significantly, the ability to have that same decision-maker driven by the same interest that would drive the decision of the child if competent, that is that child's best interests.

Advocates of the benefit test fail to explain, from a dignitarian perspective, what it is about a finding of incapacity that justifies the wholesale exclusion of the child from the decision making process and the ignorance of factors that a competent individual in identical circumstances would consider relevant in making an identical decision. Such advocates simultaneously fail to explain why medical benefit is the sole concern of any such decision. An autonomous adult in the same position would pursue his/her own interests. Why are those interests subordinated to medical benefit when the autonomous adult is substituted for an incompetent child? Dignity certainly does not answer that question. To the contrary, it demands that those interests be considered.



CONCLUSION

How the genetic testing of children unable to consent should be limited is an issue which every society must grapple with. It has been argued, in line with the approach taken by international law, that genetic information is special and to be distinguished from other types of medical information. The best interests of the child is the current legal regulator of parental decision making for children who lack capacity. However, this test has crept into the legal management of competent child decision making in the United Kingdom. Circumventing competent child decision making by applying best interests to a competent child or, alternatively, collapsing the best interests of the child and the child's competence into one enquiry, undermine a child's autonomy. This paper has argued against such an approach being adopted in New Zealand. Yet, ousting best interests for competent children would not prevent judges from ensuring that the right decision be made in the circumstances. Rather, it would ensure that judges undertake a detailed and transparent analysis of a child's competence. If a judge is satisfied that the person before them is competent, then they should not interfere. On the other hand, if they are not competent, then the best interests standard comes into play.

It is argued that the best interests of the child should be the overarching limitation on parental authority to consent to a genetic test on behalf of their non-competent child. The best interests fetter on parental decision making, contrary to the HGRP recommendations, is to be preferred over a benefit test. This is so for the following reasons.

First, it has been shown that in international law, best interests and benefit are distinct concepts. Upon a closer analysis, four main differences can be described. First, best

interests incorporates a mechanism of optimising options. Benefit provides no such guidance. Second, best interests employs a language of interests. It can be fairly stated that all rights are interests, although all interests are not necessarily rights. Therefore, interests will necessarily incorporate the rights of the child, including the child's right to express his or her views. This leads us to the third difference. Benefit provides no ability for the child's views to be taken into account and therefore differs procedurally to best interests. A child's right to participation is ignored. Finally, although the benefit test could potentially be interpreted generously,³⁹⁷ neither international law nor judicial practice supports such a broad interpretation.

Given that a benefit test does substantively and procedurally differ from a best interests test, application of such a test would fail to comply with Article 3 of the CRC. This Article is now considered to be a general principle of interpretation in international law. Although the best interests standard has some flaws, this paper does not perceive them as fatal and has presented responses to the general criticisms mounted against it.

Finally, the best interests test facilitates the dignity of the child to a better degree than the benefit test would. This is so because the benefit test fails to incorporate a language of interests and therefore misses an analysis of the child's autonomy, the child's views and the child's right not to know. All of these interests/rights require examination under a best interests test - benefit demands no such consideration. In this way, a benefit test does not afford children full protection of their dignity. This alone is reason enough to reject it.

³⁹⁷ See for example Skegg's definition in the context of the s 36 incorporation of the expression "benefit" as a potential limitation on 16 and 17 year olds decision making: Skegg and Paterson above n 100, 171-203. This is discussed in Section 1, Part 3.

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