
Genetics, Parenting, and Children's Rights in the Twenty-First Century

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Not only do genetic traits sometimes translate into physical and mental illnesses, they may also manifest themselves as tendencies towards certain behaviours. This discovery has led to the misinterpretation and misapplication of genetic information, and has been directed to unforeseen uses, from criminal defence to genetic racism. The issue is especially sensitive when deciding if and when parents should have access to the genetic information of their children.

The author begins with an overview of the principles of behavioural genetics and types of behaviour currently under study. Next, the social and psychological risks associated with genetic testing are presented, along with guidelines necessary to distinguish between testing which is therapeutic and that which is non-therapeutic. The distinction is a crucial one, as the author proposes a therapeutic-benefit test, advocating testing only where an effective intervention is available.

Finally, the author concludes that legislation is the more appropriate medium for defining the extent of parental rights once intervention is allowed rather than leaving physicians to decide on a case-by-case basis.

Non seulement certains traits génétiques se traduisent-ils par des maladies physiques et mentales, mais d'autres se manifestent par des prédispositions à certains comportements. Cette découverte a mené à de mauvaises interprétations et applications de l'information génétique, ainsi qu'à des usages imprévus, dont son utilisation en défense dans le contexte du droit pénal et le racisme génétique. Les questions soulevées sont particulièrement délicates lorsqu'il s'agit de décider si, et à quel moment, les parents devraient avoir accès à l'information génétique relative à leurs enfants.

L'auteur commence par un survol des principes de la génétique comportementale et de certains types de comportement actuellement sous étude. Il fait ensuite état des risques sociaux et psychologiques associés au dépistage génétique, et met de l'avant des lignes directrices pour distinguer le dépistage thérapeutique du dépistage non-thérapeutique. La distinction est cruciale, car l'auteur propose que le test en soit un de bénéfice thérapeutique, en vertu duquel le dépistage ne serait effectué que lorsqu'il existe un traitement efficace.

L'auteur conclut que l'intervention du législateur constituerait le moyen le plus approprié de définir l'étendue des droits parentaux une fois que l'intervention a été permise, plutôt que de laisser aux médecins l'autorité de décider au cas par cas.

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Introduction

As genetic readouts increase in power and decrease in cost, the potential for intrusive applications will skyrocket. Future ELSI [ethical, legal and social issues] efforts will require acute scientific vision to anticipate the problems and propose safeguards.¹

Eric S. Lander, Massachusetts Institute of Technology, U.S.A.

The effects of these technologies seem beneficial in the here and now; it is the future consequences that are worrisome.²

Lee M. Silver, Princeton University, U.S.A.

In October of 1993, a group of distinguished scientists from the Department of Human Genetics, University Hospital Nijmegen, and the Neuroscience Center of the Massachusetts General Hospital reported an association between the gene that codes for monoamine oxidase A ("MAOA") and some abnormal behaviours, including arson, attempted rape, and exhibitionism.³ Following publication, these scientists were not only "stunned" by the general confusion and misinterpretation of their data but also by the way certain members of society were willing to apply their findings. The first individuals to demonstrate their eagerness to make use of these data were criminal defense attorneys who "wanted to test their clients on death row for MAOA deficiency, hoping that it might exculpate them."⁴ Soon after, talk-radio hosts began to suggest that people carrying the MAOA marker should be sterilized.⁵

Genetic testing has a great deal to offer parents and their children when it comes to the prevention or treatment of illnesses for which there exists a definitive therapeutic intervention (surgical, pharmacological, and/or dietary) of proven efficacy. In the absence of early detection and prevention, many genetic imperfections can translate into physical as well as mental illnesses. For instance, testing for familial polyposis coli followed by subsequent removal of the colon in the early teenage years can prevent the onset of cancer.⁶ Early testing for phenylketonuria, a single gene metabolic disorder, followed by subsequent dietary treatment in newborns can prevent the de-

¹ E.S. Lander, "The New Genomics: Global Views of Biology" (1996) 274 *Science* 536 at 538.

² L.M. Silver, *Remaking Eden: How Genetic Engineering and Cloning will Transform the American Family* (New York: Avon Books, 1998).

³ H.G. Brunner *et al.*, "Abnormal Behavior Associated with a Point Mutation in the Structural Gene for Monoamine Oxidase A" (1993) 262 *Science* 578.

⁴ C.C. Mann, "Behavioral Genetics in Transition" (1994) 264 *Science* 1686 at 1689.

⁵ *Ibid.*

⁶ P.A. Gabow, "Autosomal Dominant Polycystic Kidney Disease" (1993) 329 *New Engl. J. Med.* 332. Other examples of the benefit of early genetic testing include the prevention of familial hypertrophic cardiomyopathy with drug therapy (see B.J. Maron *et al.*, "Hypertrophic Cardiomyopathy: Interrelations of Clinical Manifestations, Pathophysiology, and Therapy" (1987) 316 *New Engl. J. Med.* 844) and the prevention of familial hyperlipidemia with dietary restrictions (see J.A. Cortner *et al.*, "Familial Combined Hyperlipidemia in Children: Clinical Expression, Metabolic Defects, and Management" (1993) 123 *J. Pediatr.* 177).

velopment of mental retardation.⁷ This paper will focus on the important issue of parental rights vis-à-vis their children's biobehavioural information. More specifically, the purpose of this paper is to consider whether parents ought to have a restricted or an unrestricted right of access to the information contained in their children's genome.

The need for precaution as biotechnology progresses will be particularly pronounced when deciding which genetic tests and interventions ought to be approved for clinical practice. Given that genetic biotechnology is still in its infancy, it is difficult to assess the biological, psychological, and socioeconomic risks that genetic technology may pose to individual users. It is even more difficult to predict the cumulative effects that genetic technology may have on society following long-term clinical application.

Genetic research clearly has a powerful impact on society, which is partly attributable to the perceived association between *scientific* information and *proven* information. Few people would question information that has been verified scientifically, despite the fact that what science proves today it may disprove tomorrow. In the twenty-first century, scientists will uncover a large and expanding quantity of gene-behaviour associations. Such discoveries will raise new and interesting ethical and legal dilemmas. Among the most significant future issues will be the need to decide who should and should not have a right to access behavioural genetic information.

In light of these uncertainties, it is suggested that we adopt an approach to decision-making based on reasoned restraint. That is, for the time being, it is suggested that only those genetic interventions offering *immediate therapeutic benefits* should be approved for clinical practice. For instance, genetic testing can be said to offer "immediate benefits" when it provides the patient or user with more than just predictive information: secondary interventions of proven efficacy must also be available in the event of a positive test result. In addition, genetic testing will only qualify as "therapeutic" when the benefits of testing clearly outweigh the associated risks of harms. When it comes to the application of genetic interventions to children, only those interventions offering immediate therapeutic benefits *to the child* should be approved for clinical practice.

As our science evolves and as we gain better insight into the actual costs and benefits of various behavioural genetic interventions, the need may arise to redefine the precautionary boundary that is originally set to separate those interventions to which parents have access (interventions offering immediate therapeutic benefits to the child) from those to which they do not (interventions offering no immediate therapeutic benefits to the child). In the meantime, it would be wise to leave the door open to the possibility of permitting exemptions from the general rule since exceptional and currently unforeseeable circumstances may arise in which it would be in the child's

⁷ C.M. Laberge & B.M. Knoppers, "Genetic Screening: From Newborns to DNA Typing" in C.M. Laberge & B.M. Knoppers, eds., *Genetic Screening: From Newborns to DNA Typing* (Amsterdam: Elsevier Science, 1990) 379.

best interests to allow his or her parents access to genetic interventions notwithstanding the absence of immediately visible therapeutic benefits.

I. What is Behavioural Genetics?

A. Basic Principles and Scientific Method

The basic principle underlying behavioural genetic research is that our genes are responsible for the neuroanatomical and biochemical functioning of our brains and nervous systems which interact with the environment to produce behaviour. Ignoring for the moment the important role played by the environment, differences in behaviour can be explained by individual differences in genetic makeup since such differences result in the fact that we do not all share identically functioning brains. To use the example of the reported link between the MAOA gene and abnormally aggressive behaviour, a defect in the gene coding for MAOA leads to an inability of this enzyme to metabolize certain chemicals in the brain leading in turn to an increased propensity towards abnormal behaviour such as arson, attempted rape, and exhibitionism in certain individuals.⁸

Two general categories of behavioural genetic research currently exist: quantitative genetic research and molecular genetic research. Quantitative genetic research attempts to estimate the magnitude or size of the contribution of genetics to behaviour without trying to localize the particular gene or genes responsible.⁹ Quantitative genetic methods include family, twin, and adoption studies. The most important among these is probably the study of twins. Identical twins are genetically identical whereas only half of the genes in fraternal twins, as with ordinary siblings, are identical. Thus, if heredity affects behaviour, one would expect a greater degree of similarity in the behaviour of identical twins than in the behaviour of fraternal twins. In other words, one might expect the personalities of identical twins to be more similar than the personalities of normal siblings or fraternal twins.

Molecular genetics attempts to isolate the particular gene or genes associated with a given behaviour.¹⁰ Scientists employ statistics to uncover whether a particular genetic marker or allele can be correlated with the presence of a particular phenotype, an observable characteristic such as a behavioural trait or a disease that is expressed by certain groups of individuals. For example, Alzheimer's disease is now known to be associated with the presence of a genetic mutation on the gene coding for the apolipoprotein E.¹¹

⁸ Brunner *et al.*, *supra* note 3.

⁹ P.R. Billings, J. Beckwith & J.S. Alper, "The Genetic Analysis of Human Behavior: A New Era?" (1992) 35 Soc. Sci. Med. 227.

¹⁰ R. Plomin, "Genes and Behaviour" (1993) 27 Ann. Med. 503.

¹¹ C.L. Lendon *et al.*, "Exploring the Etiology of Alzheimer Disease Using Molecular Genetics" (1997) 277 J. Am. Med. Assoc. 825 at 828.

The contribution of genetics to most behavioural traits is likely to be exceedingly complex. Although some behavioural traits and diseases, such as Huntington's disease, are caused by a single gene with little effect from other genes or the environmental background,¹² most behavioural traits appear to be influenced by many genes, each with small effects, as well as by nongenetic environmental factors.¹³ Thus, in most cases, it will be incorrect to state that a gene or series of genes *cause* behaviour. At best, genes contribute to or are associated with behavioural characteristics.

B. Current and Future Applications of Behavioural Genetics

The Human Genome Project, which had its formal start in 1990, is scheduled for completion in the year 2003.¹⁴ By that time, it is hoped that the sequence and location of our estimated 100,000 genes will have been determined. Genetic researchers will then be able to concentrate their efforts on uncovering the functioning of these genes, that is, the way in which individual genes or gene clusters predispose people to different behaviours. As we accumulate information concerning the location and function of genes, remarkable advances in diagnosis and genetic manipulation will emerge.

1. Current Applications of Genetic Diagnosis

Genetic testing is already being used for a number of different purposes. One purpose is the screening of children for genetic diseases. As is argued in this paper, while the benefits of early diagnosis clearly outweigh the risks of harms in the case of preventing serious, early-onset, causative illnesses, the risk-benefit ratio is less clear in the case of susceptibility illnesses as well as late-onset illnesses for which there are no effective interventions.

Genetic testing is also being used to assist couples in making decisions about the termination of a pregnancy. Couples who are not religiously or ethically opposed to abortion are using genetic testing to prevent the transmission of serious genetic diseases.¹⁵ For instance, it has been reported that 92% of prenatally diagnosed cases of Down's syndrome end in termination.¹⁶ Leaving aside the ethics of abortion, there is a real concern that both couples and genetic counselors may be blurring the distinctions between causative and susceptibility genes by attributing more predictive power to susceptibility testing than the data allow. If so, then many couples may be basing their decisions to terminate a pregnancy on the mistaken belief that their unborn child car-

¹² Huntington's Disease Collaborative Research Group, "A Novel Gene Containing a Trinucleotide Repeat that is Expanded and Unstable on Huntington's Disease Chromosomes" (1993) 72 *Cell* 971.

¹³ R. Plomin, "The Role of Inheritance in Behavior" (1990) 248 *Science* 183; see also P. McGuffin & N. Martin, "Science, Medicine, and the Future: Behaviour and Genes" (1999) 319 *Brit. Med. J.* 37.

¹⁴ M.D. Lemonick & D. Thompson, "Racing to Map our DNA" *Time* 153:1 (11 January 1999) 28 at 30.

¹⁵ J.F. Botkin, "Fetal Privacy and Confidentiality" (1995) 25:5 *Hastings Cent. Rpt.* 32.

¹⁶ E. Alberman *et al.*, "Down's Syndrome Births and Pregnancy Terminations in 1989 to 1993: Preliminary Findings" (1995) 102 *Brit. J. Obs. & Gyn.* 445.

ries a gene(s) that *will* cause disease when really the unborn child carries a gene(s) that *predisposes* him or her to a given illness.

An alternative to selective pregnancy termination that also makes use of genetic testing in order to prevent the transmission of genetic illnesses is preimplantation genetic diagnosis ("PGD"). PGD involves the genetic screening of embryos created from the couple's DNA followed by the selective transfer into the woman's uterus of only those embryos that are diagnosed as unaffected.¹⁷ Since its introduction in 1990,¹⁸ PGD has enabled couples to prevent the transmission of genetic illnesses such as cystic fibrosis,¹⁹ Tay-Sachs disease²⁰ and sickle cell anemia.²¹ For the time being, however, PGD's clinical application is limited to a relatively small number of single gene anomalies, X-linked disorders, and chromosomal abnormalities.²²

2. Future Applications of Genetic Diagnosis

In the future, genetic testing will become powerful enough to provide couples with probability estimates of each and every disease characteristic as well as behavioural traits to which their children are genetically predisposed. Genetic "read-outs" might include not only a list of the child's basic personality predispositions (*e.g.* type-A personality) but also a list of any behavioural illnesses (*e.g.* schizophrenia) and deviant behavioural characteristics (*e.g.* substance abuse) that the child is at risk of developing: "A new technology called DNA chips ... will make an entire DNA blueprint as easy to read as a supermarket bar code."²³

As the science of genetics matures, it will become possible for couples to combine the predictive information provided by the child's genetic read-out with environmental interventions, PGD technology and genetic manipulation technology. Genetic testing may one day be used to supplement environmental interventions (such as modeling appropriate behaviours, rewarding desirable behaviours, punishing unwanted behaviours, etc.) in the shaping of children's personalities by providing parents with "advanced notice" of the entire gamut of behavioural traits to which their children are genetically predisposed. For instance, parents whose child has a genetic

¹⁷ J.D.A. Delhanty & J.C. Harper, "Genetic Diagnosis Before Implantation" (1997) 315 *Brit. Med. J.* 828.

¹⁸ A.H. Handyside *et al.*, "Pregnancies from Biopsied Human Preimplantation Embryos Sexed by Y-Specific DNA Amplification" (1990) 344 *Nature* 768.

¹⁹ A.H. Handyside *et al.*, "Birth of a Normal Girl After In Vitro Fertilization and Preimplantation Diagnostic Testing for Cystic Fibrosis" (1992) 327 *New Engl. J. Med.* 905.

²⁰ W.E. Gibbons *et al.*, "Preimplantation Genetic Diagnosis for Tay-Sachs Disease: Successful Pregnancy after Pre-embryo Biopsy and Gene Amplification by Polymerase Chain Reaction" (1995) 63 *Fertil. & Steril.* 723.

²¹ K. Xu *et al.*, "First Unaffected Pregnancy Using Preimplantation Genetic Diagnosis for Sickle Cell Anemia" (1999) 281 *J. Am. Med. Assoc.* 1701.

²² A.-M. Nagy *et al.*, "Scientific and Ethical Issues of Preimplantation Diagnosis" (1998) 30 *Ann. Med.* 1.

²³ D. Haner & P. Copeland, *Living with Our Genes* (New York: Doubleday, 1998) at 303.

predisposition towards substance abuse may stand a better chance of curbing or preventing the onset of such behaviour if they are provided with advanced notice of their child's predisposition.

Advances in PGD technology will permit couples to analyze the genetic profiles of a large number of embryos created from their own DNA and then to select a preferred embryo for implantation. For instance, a couple choosing among ninety-six profiles might begin by eliminating all those embryos whose genome contains chromosomal abnormalities or severe genetic defects. Assuming that thirty-three embryos are eliminated, this would reduce the pool down to sixty-three remaining embryos. The couple might then exclude those embryos whose genome would predispose it to physical or cognitive phenotypes that are below average as well as those embryos whose genome would predispose it to deviant behavioural characteristics such as substance abuse or criminality. By a process of elimination, couples will be able to select the embryo that conforms best to their expectations.

An inherent limitation to PGD technology is that the genetic constitution of the selected embryo is constrained by the genetic makeup of the biological parents. However, advances in genetic manipulation technology will permit scientists to *add* genes or gene clusters that code for specific physical or cognitive characteristics. Amazingly, scientists will not be limited to the addition of human characteristics since it will also be possible to include certain animal characteristics. For instance, among other things, we may one day be able to appropriate light-emitting organs from fireflies or fish, generators of electricity from eels and magnetic detection systems from birds.²⁴ Scientists have already managed to create mice that glow green under ultraviolet light by transferring a foreign gene that codes for green fluorescent protein into mice embryos.²⁵ These additions may someday enable humans to have night vision, an extremely sophisticated sense of smell or even the ability to distinguish different radio frequencies instead of light frequencies. Silver has observed that

[o]ver the next two centuries, the number and variety of possible genetic extensions to the basic human genome will rise exponentially—like the additions to computer operating systems that occurred during the 1980s and 90s. Extensions that were once unimaginable will become indispensable... to those parents who are able to afford them.²⁶

II. Which Behaviours Have Already Been Studied?

The purpose of this section of the paper is simply to provide the reader with an overview of some of the behaviours that have already been studied by behavioural geneticists. Four categories of behaviours can be distinguished. The first category in-

²⁴ Silver, *supra* note 2.

²⁵ A.C.F. Perry *et al.*, "Mammalian Transgenesis by Intracytoplasmic Sperm Injection" (1999) 284 *Science* 1180.

²⁶ Silver, *supra* note 2 at 280.

cludes those behaviours that have conventionally been referred to as "behavioural illnesses."²⁷ Within this category, scientists have already reported putative gene-behaviour associations for, *inter alia*, depression,²⁸ schizophrenia,²⁹ Alzheimer's,³⁰ autism,³¹ attention-deficit hyperactivity disorder,³² and Tourette's syndrome.³³

The second category includes those behaviours that are largely perceived as being "deviant or non-normative characteristics". Published reports of associations between these behaviours and particular genetic *loci* have consistently led to significant publicity and controversy since these behaviours are usually political in nature by virtue of being highly susceptible to stigmatization and discrimination.³⁴ Examples of behaviours falling within this second category include alcoholism,³⁵ criminality,³⁶ homosexuality,³⁷ and substance abuse.³⁸

²⁷ Those behaviours that have been included in the diagnostic and statistical manual of mental disorders of the American Psychiatric Association. See American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders, DSM-IV*, 4th ed. (Washington, D.C.: American Psychiatric Association, 1994).

²⁸ K.S. Kendler *et al.*, "A Population-Based Twin Study of Major Depression in Women: The Impact of Varying Definitions of Illness" (1992) 49 *Arch. Gen. Psychiatry* 257; E. Marshall, "Manic Depression: Highs and Lows on the Research Roller Coaster" (1994) 264 *Science* 1693; P. McGuffin *et al.*, "A Hospital-Based Twin Registry of the Heritability of DSM-IV Unipolar Depression" (1996) 53 *Arch. Gen. Psychiatry* 129.

²⁹ L. Peltonen, "Schizophrenia: All Out for Chromosome Six" (1995) 378 *Nature* 665; E.S. Gershon *et al.*, "Closing in on Genes for Manic-Depressive Illness and Schizophrenia" (1998) 18 *Neuropsychopharmacology* 233.

³⁰ P.H. St. George-Hyslop *et al.*, "The Genetic Defect Causing Familial Alzheimer's Disease Maps on Chromosome 21" (1987) 235 *Science* 885; D. Blacker *et al.*, "ApoE-4 and Age at Onset of Alzheimer's Disease: The NIMH Genetics Initiative" (1997) 48 *Neurology* 139.

³¹ A. Bailey *et al.*, "Autism as a Strong Genetic Disorder: Evidence from a British Twin Study" (1995) 25 *Psychol. Med.* 63.

³² A. Thapar, A. Hervas & P. McGuffin, "Childhood Hyperactivity Scores are Highly Heritable and Show Sibling Competition Effects: Twin Study Evidence" (1995) 25 *Behav. Genet.* 537; A. Thapar *et al.*, "Genetic Basis of Attention Deficit and Hyperactivity" (1999) 174 *Brit. J. Psychiatry* 105.

³³ R.A. Price *et al.*, "A Twin Study of Tourette Syndrome" (1985) 42 *Arch. Gen. Psychiatry* 815; D.L. Pauls & J.F. Leckman, "The Inheritance of Gilles de la Tourette's Syndrome and Associated Behaviors: Evidence for Autosomal Dominant Transmission" (1986) 315 *New Engl. J. Med.* 993.

³⁴ M. Simm, "Violence Study Hits a Nerve in Germany" (1994) 264 *Science* 653; L. Goodman, "Crime and Genetics Conference Breeds Further Controversy" (1995) 377 *Nature* 276; D. Butler, "Geneticist Quits in Protest at 'Genes and Violence' Claim" (1995) 378 *Nature* 224; "Genome Research Risks Abuse, Panel Warns" Editorial Comment (1995) 378 *Nature* 529; T. Beardsley, "Crime and Punishment: Meeting on Genes and Behavior Gets Only Slightly Violent" *Scientific American* 273:6 (December 1995) 19.

³⁵ K.R. Merinkangas, "The Genetic Epidemiology of Alcoholism" Editorial (1990) 20 *Psychol. Med.* 11; K.S. Kendler *et al.*, "A Population-Based Twin Study of Alcoholism in Women" (1992) 268 *J. Am. Med. Assoc.* 1877; R.W. Karp, "Genetic Studies in Alcohol Research" (1994) 54 *Am. J. Med. Genet.* 304; C. Holden, "New Clues to Alcoholism Risk" (1998) 280 *Science* 1348.

The third category consists of cognitive characteristics such as reading disabilities³⁶ and intelligence,³⁷ characteristics that cannot be properly classified as behaviours *per se*. The final category of behaviours that are currently being studied by scientists includes those behaviours that might be termed "basic personality predispositions".³⁸ For instance, scientists are trying to ascertain the genetic *loci* of personality traits such as impulsivity, shyness, self-esteem, social attitudes, and novelty seeking.³⁹ Even stuttering has received the attention of behavioural geneticists.⁴⁰

III. Risks Associated With Behavioural Genetic Testing

A. The Risk of Neurogenetic Determinism

What does it mean to say that someone is genetically predisposed to expressing certain types of behaviour? Will all carriers of the predisposition necessarily exhibit the behaviour? Predisposition testing cannot accurately predict when, where, or even if a behavioural characteristic will find expression: "Even if there were a correlation between, say, a single-gene defect and a predisposition to impulsivity, no amount of

³⁶ M. Bohman *et al.*, "Predisposition to Petty Criminality in Swedish Adoptees" (1982) 41 Arch. Gen. Psychiatry 1233; S.A. Mednick, W.F. Gabrielli Jr. & B. Hutchings, "Genetic Influences in Criminal Convictions: Evidence from an Adoption Cohort" (1984) 224 Science 891.

³⁷ J.M. Bailey *et al.*, "Heritable Factors Influence Sexual Orientation in Women" (1993) 50 Arch. Gen. Psychiatry 217; D.H. Hamer *et al.*, "A Linkage Between DNA Markers on the X Chromosome and Male Sexual Orientation" (1993) 261 Science 321; S. LeVay & D.H. Hamer, "Evidence for a Biological Influence in Male Homosexuality" *Scientific American* 270:5 (May 1994) 44.

³⁸ R.J. Cadoret *et al.*, "An Adoption Study of Genetic and Environmental Factors in Drug Abuse" (1986) 43 Arch. Gen. Psychiatry 1131; R.W. Pickens *et al.*, "Heterogeneity in the Inheritance of Alcoholism" (1991) 48 Arch. Gen. Psychiatry 19; G.R. Uhl, A.M. Persico & S.S. Smith, "Current Excitement With D₂ Dopamine Receptor Gene Alleles in Substance Abuse" (1992) 49 Arch. Gen. Psychiatry 157; H.W. Gordon, "Human Neuroscience at National Institute on Drug Abuse: Implications for Genetic Research" (1994) 54 Am. J. Med. Genet. 300.

³⁹ L.R. Cardon *et al.*, "Quantitative Trait Locus for Reading Disability on Chromosome 6" (1994) 266 Science 276.

⁴⁰ T.J. Bouchard Jr. & M. McGue, "Familial Studies of Intelligence: A Review" (1981) 212 Science 1055; T.J. Bouchard Jr. *et al.*, "Sources of Human Psychological Differences: The Minnesota Study of Twins Reared Apart" (1990) 250 Science 223; R. Plomin *et al.*, "DNA Markers Associated with High Versus Low IQ: The IQ Quantitative Trait Loci (QTL) Project" (1994) 24 Behav. Genet. 107.

⁴¹ This category includes behaviours such as altruism, empathy, optimism, and neuroticism that are normally studied by personality or social psychologists.

⁴² C.R. Cloninger, R. Adolfsson & N.M. Svrakic, "Mapping Genes for Human Personality" (1996) 12 Nat. Genet. 3; J. Benjamin *et al.*, "Population and Familial Association between the D4 Dopamine Receptor Gene and Measures of Novelty Seeking" (1996) 12 Nat. Genet. 81; R.P. Ebstein *et al.*, "Dopamine D4 Receptor (D4DR) Exon III Polymorphism Associated with the Human Personality Trait of Novelty Seeking" (1996) 12 Nat. Genet. 78.

⁴³ G. Andrews *et al.*, "Genetic Factors in Stuttering Confirmed (1991) 48 Arch. Gen. Psychiatry 1034; C.D. Mellon, F. Umar & M.L. Hanson, "Stuttering as a Phenotype for Behavioral Genetics Research" (1993) 48 Am. J. Med. Genet. 179.

behavioural genetics could predict whether such a predisposition will gain expression in a bar room—or a board room—fight.”⁴⁴ Moreover, many individuals possessing genes that predispose them to certain forms of behaviour may never express those behaviours, while many other individuals not possessing the predisposing genes may habitually express the behaviours.

The reason for all this uncertainty is of course that genetics is only one factor amongst many that contributes to behaviour. Non-genetic factors, such as the environment, are also significant contributors to the expression and development of behaviour characteristics.⁴⁵ According to Dean Hamer of the National Cancer Institute in the U.S., “complex behavioural traits ... are the product of multiple genetic and environmental antecedents, with ‘environment’ meaning not only the social environment but also such factors as the ‘flux of hormones during development, whether you were lying on your right or left side in the womb, and a whole parade of other things.’”⁴⁶ The interaction between genes and environment is so complex that “[g]enes might have a somewhat different effect on someone in Salt Lake City than if that person were growing up in New York City.”⁴⁷

The potential for misinterpretation and misapplication of behavioural genetic research has been said to constitute one of the significant risks associated with the genetics movement. Some commentators have voiced their concern that society will begin to believe in the existence of a direct and causal relationship between genetics and behaviour. Consequently, whereas non-genetically influenced behaviour will be seen as malleable and the product of free will, genetically influenced behaviour will be misinterpreted as being unmalleable and beyond the control of the affected individual. This belief has been referred to as “neurogenetic determinism”⁴⁸ or “genetic fatalism”.⁴⁹

If behaviour is a consequence of genetics rather than the result of free choice, then should individuals be held less accountable, legally and morally, for behaviour that is genetically influenced than for behaviour that is non-genetically influenced? For instance, if it is recognized that some forms of alcoholism are genetic and others are environmental, “there may be a tendency on the part of society and of people with

⁴⁴ E. Parens, “Taking Behavioral Genetics Seriously” (1996) 26:4 *Hastings Cent. Rpt.* 13 at 14.

⁴⁵ Because genetic variance rarely accounts for more than 50% of the variance of behavioural traits, Robert Plomin has stated that one of the most important conclusions from behavioural genetic research is the significance of environmental influences on behaviour. See R. Plomin, *Nature and Nurture: An Introduction to Human Behavioral Genetics* (Pacific Grove, Cal.: Brooks/Cole Publishing, 1990).

⁴⁶ Mann, *supra* note 4 at 1687.

⁴⁷ *Ibid.*

⁴⁸ S. Rose, “The Rise of Neurogenetic Determinism” (1995) 373 *Nature* 380; S.P.R. Rose, *Lifelines: Biology, Freedom, Determinism* (Harmondsworth, U.K.: Allen Lane, 1997); S.P.R. Rose, “Neurogenetic Determinism and the New Euphenics” (1998) 317 *Brit. Med. J.* 1707.

⁴⁹ J.S. Alper & J. Beckwith, “Genetic Fatalism and Social Policy: The Implications of Behavior Genetics Research” (1993) 66 *Yale J. Biol. Med.* 511.

alcoholism themselves to blame those who have the environmentally induced form of alcoholism. According to this view, people with the environmentally induced form, unlike those with the genetic form, should have much more control over their behaviour.⁵⁰ It is this type of reasoning that motivated criminal defense attorneys to attempt to use the results of the MAOA deficiency study to exculpate their clients on death row. That is, the death row convicts should either not be held responsible for their actions or should at least receive significantly reduced sentences given that they are themselves victims of a genetic predisposition towards violence and aggression.

B. The Risk of Genetic Discrimination

Genetic discrimination is one of the most salient dangers associated with genetic testing. Health and life insurance companies as well as employers have normally been the protagonists in discussions of genetic discrimination.⁵¹ Individuals who undergo genetic testing and test positive for a predisposition to a physiological or behavioural disorder could be subjected to insurance discrimination such as the denial of insurance or exaggerated premiums. Employment discrimination includes unfavourable treatment in hiring, promotion, assignment of duties, discharge and compensation. Evidence of genetic discrimination already exists in the literature.⁵² For instance, the U.S. Air Force used to restrict carriers of sickle-cell anemia from becoming pilots on the belief that carriers, each of whom have only one copy of the sickling gene, would encounter difficulties resulting from decreased oxygen levels at high altitudes.⁵³ This has led some commentators to recommend a moratorium on the use of genetic testing by insurance companies.⁵⁴

Importantly, genetic discrimination on the basis of susceptibility to a behavioural disorder is as likely as genetic discrimination on the basis of susceptibility to a physiological disorder. To name but one example, given that drunk driving is one of the most significant factors leading to car accidents, automobile insurance companies

⁵⁰ *Ibid.*

⁵¹ See generally J.S. Alper & M.R. Natowicz, "Genetic Discrimination and the Public Entities and Public Accommodations Titles of the Americans with Disabilities Act" (1993) 53 *Am. J. Hum. Genet.* 26; H. Ostrer *et al.*, "Insurance and Genetic Testing: Where are We Now?" (1993) 52 *Am. J. Hum. Genet.* 565; M.R. Natowicz, J.K. Alper & J.S. Alper, "Genetic Discrimination and the Law" (1992) 50 *Am. J. Hum. Genet.* 465; P.R. Billings *et al.*, "Discrimination as a Consequence of Genetic Testing" (1992) 50 *Am. J. Hum. Genet.* 476.

⁵² Billings *et al.*, *ibid.* at 477-78; J.E. Bowman, "Prenatal Screening for Hemoglobinopathies" (1991) 48 *Am. J. Hum. Genet.* 433 at 433; see also E.V. Lapham, C. Kozma & J.O. Weiss, "Genetic Discrimination: Perspectives of Consumers" (1996) 274 *Science* 621.

⁵³ L. Uzych, "Genetic Testing and Exclusionary Practices in the Workplace" (1986) 7 *J. Pub. Health Pol'y* 37 at 50.

⁵⁴ P.S. Harper, "Genetic Testing and Insurance" (1992) 26 *J. Royal College Phys. Lond.* 184 at 187; P.S. Harper, "Insurance and Genetic Testing" (1993) 341 *Lancet* 224; F. Gammie, "Genetic Test Report Urges Moratorium on Disclosure" (1993) 366 *Nature* 498.

may be tempted to either deny insurance or charge exaggerated premiums to individuals carrying a gene(s) predisposing them to alcoholism.

Many observers, including Jonathan Beckwith, a geneticist at Harvard University, have noted that the threat of genetic discrimination and stigmatization will likely extend well beyond the realm of insurance and employment. Mann has observed, "[O]ne wonders why it should be assumed the process [of stigmatization] will stop with insurance companies"⁵⁵. Indeed, social stigmatization on the basis of genetics could become as prevalent as economic stigmatization. For instance, Princeton University biologist Lee Silver has hypothesized that advances in genetic research may eventually lead to a divided society, the "gen-rich" and the "gen-poor", those with and without engineered genomes.⁵⁶ Although it is impossible to foresee with precision how genetic labeling will impact future social structures, genetic elitism and new forms of social hierarchies reminiscent of the novel *Gattaca*, as well as mating and reproductive decision-making on the basis of genetics may not be unlikely possibilities.

Critics of behavioural genetics predict that genetic racism will be the most prevalent form of racism in the twenty-first century; genetic makeup will replace skin colour as the new basis for holding prejudicial beliefs and attitudes. Peter Breggin, a psychiatrist at the Center for the Study of Psychiatry in Bethesda, Maryland has noted that "[b]ehavioral genetics is the same old stuff in new clothes, ... [i]t's another way for a violent, racist society to say people's problems are their own fault, because they carry 'bad' genes."⁵⁷ For instance, individuals carrying "bad genes" predisposing them to schizophrenia may find that adoption agencies are rejecting their applications on the assumption that they are unfit for parenthood. Individuals carrying "bad genes" predisposing them to reading disabilities or reduced cognitive abilities may be denied entrance to private high schools or colleges.

C. Impact of Testing on the Child and on Intrafamilial Relationships

Another disadvantage to genetic testing is that unfavourable results may disrupt intrafamilial relationships and damage the self-esteem of children whose genetic makeup is not up to par. Research has shown that children who test positive for a predisposition to a behavioural illness may suffer a loss of self-esteem, may be overindulged, rejected or treated as a scapegoat by family,⁵⁸ and "[i]f a child's genetic infor-

⁵⁵ Mann, *supra* note 4 at 1689.

⁵⁶ Silver, *supra* note 2.

⁵⁷ Mann, *supra* note 4 at 1686.

⁵⁸ See American Society of Human Genetics Board of Directors and The American College of Medical Genetics Board of Directors, "Points to Consider: Ethical, Legal, and Psychosocial Implications of Genetic Testing in Children and Adolescents" (1995) 57 Am. J. Hum. Genet. 1233 [hereinafter "Points to Consider"]. See also E.C. Perrin & P.S. Gerrity, "There's a Demon in Your Belly: Children's Understanding of Illness" (1981) 67 *Pedia.* 841; J.H. Fanos & J.P. Johnson, "Barriers to Carrier Testing for CF Siblings" (1993) 53 (suppl.) Am. J. Hum. Genet. 51; N.S. Wexler, "Genetic Jeopardy and the New Clairvoyance" (1985) 6 *Prog. Med. Genet.* 277; S. Kessler, "Invited Essay on

mation is disclosed outside the family, the ensuing loss of privacy may exacerbate poor self-esteem⁵⁹ and lead to significant psychological trauma.

Parents may not always be aware of the potentially adverse psychosocial effects that testing can have on the child's own cognition as well as on parent-child and sibling-sibling bonds: "In requesting testing, parents usually envisage the benefits of a negative test result: reduction in anxiety for themselves and the child and ability to make firm plans for the future. They are less likely to be aware of the potential harms of a positive test result."⁶⁰ For instance, homophobic parents might request testing to determine whether their child carries the gene(s) predisposing him or her to homosexuality. They may feel confident that testing is in the best interests of their child and family. They may reason that a negative test result would reduce anxiety for themselves and a positive result would provide them with sufficient advanced notice to prevent the onset of homosexual behaviour which would, in their view, be in the child's best interests. It is easy to see how testing may not be in the child's best interests. A positive test could lead to withdrawal of affection, overprotection or rejection by the parents, stigmatization by siblings and could lead to anxiety, depression, and guilt in the child.

D. Biological Parenting

As genetic testing and genetic manipulation become increasingly refined, science may be able to significantly alter cognitive as well as basic personality predispositions. Advances in prenatal genetic engineering may permit parents to pre-select and control, to the greatest extent possible, the biological component of their children's personalities. The term "biological parenting" refers to the use of advances in genetic technology by parents to shape the personalities and cognitive abilities of their children. For instance, ambitious parents may wish to request prenatal genetic manipulation to ensure that the latter are genetically predisposed to developing type-A personalities as well as above average intelligence. A 1994 Gallup public opinion poll found that 11% of those surveyed would make use of genetic manipulation to enhance the intelligence of their children if this technology were available.⁶¹ This represents a 6% increase since 1993.

the Psychological Aspects of Genetic Counseling. V. Preselection: A Family Coping Strategy in Huntington Disease" (1988) 31 *Am. J. Med. Genet.* 617. However, others have pointed out that insufficient attention has been paid to the potential harm that may be caused by withholding testing. See N.F. Sharpe, Letter to the Editor, "Presymptomatic Testing for Huntington Disease: Is there a Duty to Test those Under the Age of Eighteen Years?" (1993) 46 *Am. J. Med. Genet.* 250.

⁵⁹ "Points to Consider", *ibid.* at 1236.

⁶⁰ D.C. Wertz, J.H. Fanos & P.R. Reilly, "Genetic Testing for Children and Adolescents: Who Decides?" (1994) 272 *J. Am. Med. Assoc.* 875 at 878.

⁶¹ T. Marteau *et al.*, "Public Attitudes Towards the Selection of Desirable Characteristics in Children" (1995) 32 *J. Med. Genet.* 796 at 796. In addition, 5% of those polled would make use of genetic technology to predispose their children to "good looks", 18% of those polled would make use of genetic technology to eliminate any genetic predispositions toward "aggression" and/or "alcoholism",

Given that parents have the right to use environmental interventions to shape the personalities of their children, such as offering rewards for desirable behaviours and punishing undesirable behaviours, should parents also have the right to use biological interventions? Although there are undoubtedly many religious and ethical arguments that might be made against this proposition, a comprehensive analysis of this issue will depend on the scientific danger of tampering with groups of interacting genes, a danger which is not yet fully understood. Although the objective might be to influence a behavioural predisposition, genetic manipulation—including the removal or addition of gene(s) and gene clusters—might lead to significant metabolic, biochemical, structural, or other side effects that are not yet imaginable. Until the risks of significant genetic tampering are better understood, *primum non nocere* should be our guiding principle.

IV. Suggested Guidelines

Given the immediate and cumulative risks—individual, familial, and societal—associated with genetic testing, as well as with other genetic interventions such as genetic engineering, parental access to their children's biobehavioural information should be premised on whether testing offers immediate therapeutic benefits *to the child*. In the absence of clear therapeutic benefits, it is suggested that for the time being, parental requests for genetic testing ought to be denied.⁶² The “therapeutic-benefit” test has already been explicitly recommended as a prerequisite to genetic testing in the case of physical illnesses⁶³ and implicitly recommended in the case of behavioural illnesses.⁶⁴ As a general rule, the therapeutic-benefit test is comprised of two components. First, testing can be said to offer children immediate therapeutic benefits when preventative or early treatment interventions are available in the event of a positive test result and, second, when it accomplishes more good than harm. For instance, genetic testing for phenylketonuria offers newborns immediate therapeutic

and 10% of those polled would make use of genetic technology to eliminate any genetic predispositions toward “homosexuality”.

⁶² One exception to this rule, which is reviewed below, is the case of monogenic behaviours posing immediate and serious risks or harms to the child. Even where no therapeutic intervention is available, testing may be justified

⁶³ Clinical Genetics Society (U.K.), “The Genetic Testing of Children” (1993) 31 *J. Med. Genet.* 785; L.B. Andrews *et al.*, eds., *Assessing Genetic Risks: Implications for Health and Social Policy* (Washington, D.C.: National Academy Press, 1994); “Points to Consider”, *supra* note 58; P.S. Harper & A. Clarke, “Should We Test Children for ‘Adult’ Genetic Diseases?” (1990) 335 *Lancet* 1205.

⁶⁴ For instance, the International Huntington Association and the World Federation of Neurology have issued a policy statement recommending that genetic testing for Huntington's disease, a late-onset adult behavioural disorder for which there is currently no prevention or early treatment available, not be offered to parents. See International Huntington Association and the World Federation of Neurology Research Group on Huntington's Chorea, “Guidelines for the Molecular Genetics Predictive Test in Huntington's Disease” (1994) 31 *J. Med. Genet.* 555 [hereinafter “Predictive Test in Huntington's Disease”].

benefits given that subsequent dietary treatment can prevent them from developing mental retardation.⁶⁵

Although testing clearly leads to immediate therapeutic benefits for children in the case of phenylketonuria, the determination as to whether testing is therapeutically beneficial in other cases will undoubtedly become an area of uncertainty as increasing numbers of behaviours become susceptible to genetic testing. Fortunately, two criteria may be used to offer guidance during the intricate assessment of whether the benefits associated with a particular genetic test outweigh the risks of harm: 1) whether the behaviour is monogenic or polygenic, and 2) the immediacy and severity of the risks or harms that the behaviour poses to the child.

These criteria are valuable in that they provide a useful framework through which to examine the full range of human behaviours and in that they give content to the second component of the therapeutic-benefit test, namely the necessity of having a positive benefit-to-risk ratio. Moreover, the first component of the therapeutic-benefit test, the existence and availability of a definitive therapeutic intervention, is also amenable to being considered within the context of this framework.

Before proceeding with my analysis, it is important to mention two final points. First, the therapeutic-benefit test is meant to apply as a rule of general application. While the rule is relatively comprehensive certain exceptions are likely to apply. For instance, where the test cannot be characterized as being therapeutically beneficial to the child yet the risks associated with testing are judged to be *de minimis*, then countervailing interests such as the possible benefits of testing to the family unit may be factored into the decision-making equation.⁶⁶ Second, given the inherent complexity of genetic information and technology along with its exponential growth rate, the conclusions that are drawn in the following analysis are, to use the words of Willard Gaylin, "tentative, of a time, and receptive to immediate modification and constant re-examination."⁶⁷

A. Monogenic Behaviours Posing Immediate and Serious Risks to the Child

Although most genetic effects on behaviour are likely to be polygenic and probabilistic, others are already known to be monogenic and deterministic. Single-gene behaviours such as Tay-Sachs disease and Lesch-Nyhan Syndrome will "have their

⁶⁵ Laberge & Knoppers, *supra* note 7.

⁶⁶ This is consistent with the suggestion that parents have the power to consent to research offering no benefit to the child provided that it involves no more than a minimal risk of harm. See M.A. Somerville, *Consent to Medical Care* (Ottawa: Law Reform Commission of Canada, 1979) at 75-83 [hereinafter *Consent to Medical Care*].

⁶⁷ W. Gaylin, "Who Speaks for the Child?" in W. Gaylin & R. Macklin, eds., *Who Speaks for the Child: The Problems of Proxy Consent* (New York: Plenum, 1982) 3 at 26.

effects regardless of the environment or the genetic background of the individual."⁶⁸ In circumstances where a behaviour is both monogenic and poses immediate and significant risks or harms to the child, genetic testing will normally be justified. Parents should have the right to know when their child will *definitely* (deterministic) develop a *serious* disorder, especially when a definitive therapeutic intervention is available.

Lesch-Nyhan Syndrome is an example of a serious monogenic disorder that results in unusual motor development, mental retardation, and extreme self-mutilation.⁶⁹ Children suffering from the disorder compulsively and repetitively bite their lips, tongue and fingers. This behavioural disorder is so severe that children normally die before reaching adulthood. If a definitive therapeutic intervention were available, whether this be genetic manipulation or some form of medication, prenatal or early postnatal testing would clearly be justified. What is less clear is whether testing should be allowed when no subsequent therapeutic intervention is available. Nevertheless, the argument could be made that the certainty, immediacy, and severity associated with such behaviours provide the moral justifications for permitting parents to have access to testing, notwithstanding the absence of some form of preventative or early treatment intervention.

B. Monogenic Behaviours Whose Risks are Either Not Immediate or Not Serious

Where a single gene behaviour either does not pose serious risks to the child, such as in the case of basic personality traits,⁷⁰ or does not pose immediate risks to the child, such as in the case of late onset behavioural predispositions, testing will normally not be justified. The availability of a definitive therapeutic intervention is not relevant to this analysis given that no intervention is necessary in the case of basic personality traits and that in the case of late-onset behavioural predispositions the treatment only becomes relevant at or around the time of the behaviour's expression. The only exception to this rule is where a medical or dietary intervention in childhood can *prevent* the late onset behaviour from ever expressing itself.

Generally then, testing within this category of behaviours is to be considered non-therapeutic given that there would be no immediate therapeutic benefit to the child. Moreover, such testing would probably not even be considered therapy and would be better classified as research given that the possible side effects associated with this unnecessary testing are unknown.⁷¹ The burden of proof should be on parents to show

⁶⁸ R. Plomin, "Environment and Genes: Determinants of Behavior" (1989) 44 *Am. Psychol.* 105 at 110.

⁶⁹ J.D. Rainer, "Genetics and Psychiatry" in H.I. Kaplan & B.J. Sadock, eds., *Comprehensive Textbook of Psychiatry*, vol. 1, 4th ed. (Baltimore: Williams & Wilkins, 1985).

⁷⁰ Basic personality traits are generally considered to be polygenic.

⁷¹ See generally M.A. Somerville, "Therapeutic and Non-Therapeutic Medical Procedures—What are the Distinctions?" (1981) 2 *Health L. Can.* 85; M.A. Somerville, "Structuring the Issues in Informed Consent" (1981) 26 *McGill L.J.* 740.

why this form of genetic testing, which constitutes a non-therapeutic research intervention, should be performed on their child.

C. Polygenic Behavioural Predispositions Posing Significant Risks or Harms to the Child

The most significant difference between polygenic and monogenic behaviours is that the certainty associated with causative, single gene behaviours is absent in the case of polygenic behaviours. The probabilistic and uncertain nature of polygenic behaviours should have the effect of increasing the threshold of justification that parents would need to provide in order to have access to their child's biobehavioural information.

In the case of behavioural illnesses, so long as the potential benefits outweigh the risks, the availability of a preventative therapeutic intervention will normally justify genetic testing. For instance, if genetic manipulation were available to cure schizophrenia, then according to the therapeutic benefit rule there would be sufficient ethical justification for testing. However, in the absence of an immediately available preventative intervention testing should probably be denied. In addition to the fact that testing would offer the child few benefits, there is no certainty that the child will ever develop and express the at-risk behavioural illness.⁷² Therefore, the risks associated with testing would outweigh the benefits.

In the case of behaviours such as alcoholism or homosexuality that are often perceived as being either deviant or non-normative, great caution must be exercised in determining whether testing would be therapeutic. No broad-band characterization is possible for these behaviours. Instead, each one must be assessed individually. Taking the example of homosexuality, it is highly probable that the harms associated with testing would outweigh the benefits, if any. How should the possibility of being able to prevent homosexuality through genetic manipulation be dealt with? Should individuals have the right not to have their genomes tampered with by others—that is, to have their life determined by the genetic lottery in cases other than the prevention of serious diseases? Or, alternatively, should parents have the right to guarantee that their child will not be predisposed to becoming homosexual? If one answers yes to this latter question, then this sends the message that homosexuality is somehow abnormal, which will only serve to increase stigmatization and discrimination. If one answers no, then this removes the ability of parents to ensure that their child will not be biologically predisposed to becoming homosexual. The final decision regarding this issue will have much more to do with society's perception of normality than it will with therapeutic benefit.

⁷² As the probability estimate of developing the behaviour approaches one hundred percent, the behaviour begins to resemble a monogenic behaviour thereby serving as a stronger justification for testing.

D. Polygenic Behavioural Predispositions That do Not Pose Significant Risks or Harms to the Child

Testing should generally be denied for the largest category of polygenic behaviours, our basic personality traits. Once again, the availability of a definitive therapeutic intervention will not be relevant to the analysis of this category of behaviours. Testing for the purposes of non-therapeutic research interventions, such as biological parenting (genetic manipulation), should be strictly forbidden where there is a risk of grave and permanent consequences. Should parents be denied access when they request testing out of simple curiosity when there is no intent to subsequently tamper with child's genome? The answer will likely depend on whether the perceived and actual benefits associated with providing parents with advanced notice of their child's basic personality predispositions outweigh the perceived and actual risks of harms.

V. Limiting Parental Access to Genetic Information

A. Locus of Parental Authority and Access to Genetic Information

For centuries parents or primary care givers have been responsible for raising, protecting, educating, and caring for their children. The special parent-child relationship that is created through these parental responsibilities or incidents of guardianship as well as the theory that parents are their children's most conscientious advocates and have their children's best interests at heart form the basis of the right of parents to make health-care decisions for their children.⁷³ Other scholars have justified parental decision-making authority on the importance of preserving "intimate family relationships".⁷⁴ Either way, the authority of parents to reject or consent to medical interventions on behalf of their children is well entrenched in our common law.⁷⁵ Under the common law, interference with parental health-care decision-making authority, however beneficially intended, can give rise to a cause of action. For instance, treatment of

⁷³ L.M. Kopelman, "The Best-Interest Standard as Threshold, Ideal, and Standard of Reasonableness" (1997) 22 J. Med. Phil. 271; R.R. Faden, N.A. Holtzman & A.J. Chwalow, "Parental Rights, Child Welfare, and Public Health: The Case of PKU Screening" (1982) 72 Am. J. Public Health 1396.

⁷⁴ J. Goldstein, "Medical Care for the Child at Risk: On State Supervention of Parental Autonomy" (1977) 86 Yale L.J. 645; R.S. Downie & F. Randall, "Parenting and the Best Interests of Minors" (1997) 22 J. of Med. Phil. 219. See also *Ney v. Canada (Attorney General)* (1993), 79 B.C.L.R. (2d) 47 at 55, 102 D.L.R. (4th) 136 (S.C.) [emphasis added, hereinafter *Ney* cited to B.C.L.R.] where Justice Huddart noted that "[i]f health care is to be in a child's best interests, health care providers will need to be sensitive to and respect the culture and particularly the belief systems of the family of which the child continues to be a member, and certainly, all health care providers must be aware of the importance of family relationships to the emotional, physical, and spiritual well-being of their patient".

⁷⁵ *B. (R.) v. Children's Aid Society of Metropolitan Toronto*, [1995] 1 S.C.R. 315, 122 D.L.R. (4th) 1 [hereinafter *Children's Aid Society* cited to S.C.R.]; *Ney, ibid.*; *Consent to Medical Care, supra* note 66; B.M. Dickens, *Medico-Legal Aspects of Family Law* (Toronto: Butterworths, 1979) at 93-100.

a minor without parental consent, even non-negligent treatment, can give rise to an action for assault and battery by the parent.⁷⁶ The requirement of prior parental consent will only be exempted in limited circumstances such as in the case of emancipated minors, emergencies, or where there is statutory provision allowing functionally competent minors to provide consent to medical interventions.⁷⁷ Recently, our highest court, by a narrow majority, recognized that s. 7 of the *Canadian Charter of Rights and Freedoms* protects the right of parents to make decisions of fundamental importance for their children, including health-care decisions.⁷⁸

Parental health-care decision-making authority, however, is by no means absolute. For instance, although adults are fully entitled to refuse life-saving interventions on their own behalf, it is not at all obvious that they have the right to make such refusals on behalf of their children.⁷⁹ As will be reviewed below, courts have often exercised their *parens patriae* jurisdiction to limit the ability of parents to refuse "necessary medical interventions" on behalf of their children.⁸⁰ Of greater relevance to the issue of non-therapeutic genetic testing, parental authority has also been restricted in circumstances where parents request "inappropriate treatment" on behalf of their children.⁸¹

The general recommendation of this paper is that parents be denied access to non-therapeutic genetic information. In what way, if any, does this recommendation interfere with the decision-making authority of parents over their children, including health-care authority? In answering this question, it is perhaps wisest to begin by recalling what the therapeutic-benefit test *permits* before proceeding with an analysis as to what it excludes. Under the therapeutic-benefit test, parents would have access to all genetic tests offering therapeutic benefits to their child. The locus of authority—to reject or consent to therapeutic genetic testing—would remain with parents. What the therapeutic-benefit test would exclude is the ability of parents to consent to or demand non-therapeutic testing on behalf of their child. This limitation of parental authority is not, however, inconsistent with the current state of the law since parental authority "applies only to therapeutic treatment. They [parents] have no power to consent to

⁷⁶ E.I. Picard & G.B. Robertson, *Legal Liability of Doctors and Hospitals in Canada*, 3d ed. (Scarborough: Carswell, 1996) at 75, 107; B. Sneiderman, J.C. Irvine & P.H. Osborne, *Canadian Medical Law: An Introduction for Physicians, Nurses and other Health Care Professionals*, 2d ed. (Scarborough: Carswell, 1995) at 40.

⁷⁷ *Marshall v. Curry* (1933), 3 D.L.R. 260, 60 C.C.C. 136 (N.S.S.C. (T.D.)); *Reibl v. Hughes*, [1980] 2 S.C.R. 880, 114 D.L.R. (3d) 1. See also A.R. Holder, "Disclosure and Consent Problems in Pediatrics" (1988) 16 L. Med. & Health Care 219.

⁷⁸ *Children's Aid Society*, *supra* note 75.

⁷⁹ *Malette v. Shulman* (1990), 72 O.R. (2d) 417, 67 D.L.R. (4th) 321 (C.A.); *Fleming v. Reid* (1991), 4 O.R. (3d) 74, 82 D.L.R. (4th) 298 (C.A.); *Region 2 Hospital Corp. v. Walker* (1994), 150 N.B.R. (2d) 366, 116 D.L.R. (4th) 477 (C.A.) [hereinafter *Walker* cited to N.B.R.].

⁸⁰ See below, Part V.B.2, "Best-Interests Analysis."

⁸¹ *Ibid.*

non-therapeutic treatment for their child."⁸² In short, the therapeutic-benefit test, by authorizing access to therapeutic testing while excluding the possibility of non-therapeutic testing, neither adds nor takes away from the authority currently enjoyed by parents under the law. Instead, it merely maintains a juridical status quo.

Although my premise is that the law does *not* permit parents to insist on medical interventions that are non-therapeutic to the child, the possibility that parents may seek to assert such a right by distinguishing behavioural testing from other forms of medical testing and interventions makes it important to review the justifications that might be given for denying access to non-therapeutic behavioural testing.⁸³

B. Legal and Ethical Justifications for Denying Access to Non-Therapeutic Testing

1. Non-Maleficence and "Primum Non Nocere"

Non-maleficence or *non nocere* (do no harm) has been distinguished in biomedical ethics from *primum non nocere* (first, or above all, do no harm).⁸⁴ The latter principle has been criticized as making little sense in the modern era of scientific therapeutics.⁸⁵ The problem with *primum non nocere* is that it gives moral precedence to non-maleficence over beneficence thereby leading to therapeutic nihilism. That is, notwithstanding the important and potentially life-saving benefits associated with treatment, physicians would be morally prohibited from intervening whenever there was a risk of harming their patients.

The better view is that beneficence and non-maleficence have to be balanced or weighed against one another: "Harm may be necessary to achieve benefit, risk of harm to achieve probability of benefit."⁸⁶ For instance, a schizophrenic patient may have to endure the side effects of antipsychotic medication such as tardive dyskinesia if he or she wishes to remain lucid and unhospitalized. Therefore, where medical interventions offer therapeutic benefits to patients, a benefit-risk analysis will be required and a strict application of *primum non nocere* will make little sense.

⁸² M.L. McCall & G.B. Robertson, "Legal Rights of Children to Health Care in the Common Law Jurisdictions of Canada" in B.M. Knoppers, ed., *Canadian Child Health Law: Health Rights and Risks of Children* (Toronto: Thompson Educational, 1992) 151 at 167. See also Picard & Robertson, *supra* note 76 at 91; *E. (Mrs.) v. Eve*, [1986] 2 S.C.R. 388 at 434, 31 D.L.R. (4th) 1 [hereinafter *E. (Mrs.)* cited to S.C.R.].

⁸³ Unless the risk of harm to the child associated with the non-therapeutic intervention is trifling in which case the maxim *de minimis non curat lex* would apply. See *Consent to Medical Care*, *supra* note 66.

⁸⁴ R. Gillon, "'Primum Non Nocere' and the Principle of Non-maleficence" (1985) 291 *Brit. Med. J.* 130.

⁸⁵ R.W. Gifford, "Primum Non Nocere" (1977) 238 *J. Am. Med. Assoc.* 589.

⁸⁶ Gillon, *supra* note 84 at 131.

Where a medical intervention offers no therapeutic benefits to the patient, however, such as in the case of non-therapeutic genetic testing, *primum non nocere* makes perfect sense: "*Primum non nocere* is saying to us that if a treatment is unlikely to make much difference ... then to risk doing serious harm is hard to justify."⁸⁷ In fact, in the case of non-therapeutic interventions, there is little difference between *primum non nocere* and non-maleficence. A benefit-risk analysis is not required since the intervention is either neutral, offering neither benefits nor harms, or the intervention is associated only with the risk of harm. In either case, both *primum non nocere* and non-maleficence provide appropriate moral and legal justifications for prohibiting physicians from providing non-therapeutic genetic testing and, on the other side of the coin, for denying parents a right of access to this information in the first place.

2. Best-Interests Analysis

Another justification for denying parents a right to demand non-therapeutic genetic testing is that it would be contrary to the best interests of their child. Courts have generally relied on best interests analyses when trying to ascertain whether questionable parental decisions are based on the personal desires of the parents or on an objective analysis of the best interests of the child.⁸⁸ In circumstances where the child's best interests were not objectively discernible to the court, parental choice has generally been complied with. For example, where two standard medical interventions are available, one being recommended by the attending physician or the State and the other by the parents, and both interventions are equally fraught with potential risks and complications, courts will usually respect parental choice.⁸⁹

However, where the medical intervention recommended by the attending physician or the state is clearly in the best interests of the child by virtue of being clinically superior to the alternatives or where the parents are recommending passive non-action, courts have overridden parental choice and ordered that the life-saving intervention be performed. Two instances where courts have limited parental health-care decision making authority is where parents refuse "necessary medical interventions" on behalf of their children or where they request "inappropriate" or "non-therapeutic" treatment for their children.

One of the most common situations in which courts will restrict the ability of parents to refuse necessary treatment is where Jehovah's Witness parents refuse a blood transfusion on behalf of their child. In most cases, courts have determined that the blood transfusion would be in the child's best interests and have overridden the par-

⁸⁷ T. Brewin, "Primum Non Nocere?" (1994) 344 *Lancet* 1487 at 1488.

⁸⁸ The *parens patriae* jurisdiction of courts empowers them to step into the shoes of the parents to make orders that would be in the best interest of the child.

⁸⁹ *Re K. (L.D.)* (1985), 48 R.F.L. (2d) 164, 23 C.R.R. 337 (Ont. Prov. Ct. (Fam. Div.)); *Saskatchewan (Minister of Social Services) v. P.(F.)* (1990), 69 D.L.R. (4th) 134, [1990] 4 W.W.R. 748 (Sask. Prov. Ct.).

ent's refusal to consent.⁹⁰ Other examples include parents' refusal to consent to standard antibiotic care to treat bacterial meningitis⁹¹ or refusal to consent to operations for the treatment of cystic fibrosis.⁹² Situations in which courts have limited the ability of parents to consent to inappropriate treatment on behalf of their child include restrictions on the ability of parents to consent to the sterilization of their children⁹³ as well as on their ability to consent to the participation of their children in research.⁹⁴

Parental demands for non-therapeutic genetic testing clearly falls within the category of circumstances where a court might restrict parental authority on the basis that they are requesting inappropriate treatment that is contrary to the best interests of their child. The benefits that testing may provide to parents, such as reduced parental anxiety, are irrelevant to the best-interests analysis since it is from the perspective of the child's interests and not from the perspective of the parent's interests that the analysis must be performed.⁹⁵ Indeed, the best-interests analysis, enforced through the court's *parens patriae* jurisdiction, "exists for the benefit of those who cannot help themselves, not to relieve those who may have the burden of caring for them."⁹⁶

⁹⁰ *Re Superintendent of Family & Child Service and Dawson* (1983), 145 D.L.R. (3d) 610, [1983] 3 W.W.R. 618 (B.C. S.C.) [hereinafter *Dawson*]; *Re R.K.* (1987), 79 A.R. 140, [1987] A.J. No. 265, online: QL (AJ) (Prov. Ct. (Fam. Div.)); *Re Wintersgill and Minister of Social Services* (1981), 131 D.L.R. (3d) 184, 25 R.F.L. (2d) 395 (Sask. Unif. Fam. Ct.); *M. (R.E.D.) v. Alberta (Director of Child Welfare)* (1986), 74 A.R. 23, 47 Alta. L.R. (2d) 380 (Q.B.); *Children's Aid Society*, *supra* note 75. See also H. Rodham, "Children Under the Law" (1973) 43 Harv. Educ. Rev. 487.

⁹¹ *New Brunswick (Minister of Health & Community Services) v. B.* (1990), 106 N.B.R. (2d) 206, 70 D.L.R. (4th) 568 (N.B. Q.B. (Fam. Div.)); *Dawson*, *ibid.* See also American Academy of Pediatrics, Committee on Bioethics, "Religious Exemption from Child Abuse Statutes" (1988) 81 *Pediatr.* 169.

⁹² *Children's Aid Society of the Region of Peel v. B.(C.)* (1988), 8 A.C.W.S. (3d) 425 (Ont. Prov. Ct.).

⁹³ *E. (Mrs.)*, *supra* note 82. For British jurisprudence on the ability of parents to sterilize their mentally handicapped children, see *Re D. (a minor) (wardship: sterilization)*, [1976] 1 All E.R. 326, 2 W.L.R. 279 (Fam. D.) (where sterilization was denied on the basis that the child would likely appreciate the nature of the operation by age 18 and would be able to make her own choice) and *Re B. (a minor) (wardship: sterilization)*, [1987] 2 All E.R. 206 [1988] A.C. 199 (C.A.) (where sterilization was permitted on the basis that the seventeen year old child had no understanding of the connection between sexual intercourse and pregnancy and would be unable to care for a child on her own). See also J. Areen, "Limiting Procreation" in R.M. Veatch, ed., *Medical Ethics*, 2d. ed. (Sudbury, Mass.: Jones and Bartlett, 1997) 103.

⁹⁴ A.M. Capron, "Human Experimentation" in Veatch, *ibid.*, 135; *Consent to Medical Care*, *supra* note 66 at 75-83 (where it is suggested that parents do have the power to consent to research so long as it involves only a minimal risk of harm to the child).

⁹⁵ See *Young v. Young*, [1993] 4 S.C.R. 3 at 47, 108 D.L.R. (4th) 193, where Justice L'Heureux-Dubé commented: "The proposition is not one of 'rights'; it is one of duty and obligation to the child's best interests ... One cannot stress enough that it is *from the perspective of the child's interests* that these powers and responsibilities must be assessed, as the 'rights' of the parent are not a criterion." See also *P. (D.) v. S.(C.)*, [1993] 4 S.C.R. 141, 108 D.L.R. (4th) 287; *New Brunswick (Minister of Health & Community Services) v. C. (G.C.)*, [1988] 1 S.C.R. 1073, 85 N.B.R. (2d) 252; *Racine v. Woods*, [1983] 2 S.C.R. 173, 24 Man. R. (2d) 314; *King v. Low*, [1985] 1 S.C.R. 87, 58 A.R. 275.

⁹⁶ *E. (Mrs.)*, *supra* note 82 at 434, LaForest J.

Since testing comes at a potentially high and irreversible cost, such as the risk of serious bodily harm to the child through procedures such as non-therapeutic genetic manipulation (e.g. biological parenting) as well as the risk of moral and social harm that might result from stigmatization and discrimination, in the absence of overriding benefits to the child, testing for non-therapeutic purposes should be prohibited given that this practice would be contrary to the best interests of children.

3. Respect for the Future Autonomy of the Child

Restricting demands for non-therapeutic genetic testing can also be justified on the basis of preserving the future autonomy of the child.⁹⁷ That is, while testing for therapeutic purposes can be validated on the grounds that it is in the best interests of children and that they would have requested such testing themselves had they been competent to do so, the testing of children for non-therapeutic purposes cannot be justified on these bases and should be deferred until the "children" request such tests for themselves as adults.

In preserving the future autonomy of children, we are preserving their right to remain ignorant of their genetic status. As it has been said, "The 'right' not to know is increasingly raised as a corollary of autonomy."⁹⁸ This is a significant consideration given that knowledge of carrier status can be burdensome even for an adult. For example, despite early predictions that adults would make full use of presymptomatic genetic testing for Huntington's disease,⁹⁹ only a minority of at-risk adults actually choose to undergo such testing (approximately 10-15%).¹⁰⁰ The demand for presymptomatic genetic testing for breast cancer has also been well below expectations.¹⁰¹ It is

⁹⁷ In comparison with philosophy, the law has no definition of autonomy. Moreover, in law, the terms autonomy and self-determination are not only used interchangeably but reference to both concepts is usually made when discussing individual "rights". See M.A. Somerville, "Labels versus Contents: Variance between Philosophy, Psychiatry and Law in Concepts Governing Decision-Making" (1994) 39 McGill L.J. 179 at 185-91. Thus, the right to autonomy can exist even if the subject of the right is not yet capable of exercising his or her future autonomy. While the autonomy itself lies somewhere in the future, the right to fully enjoy this future autonomy exists in the present.

⁹⁸ B.M. Knoppers & R. Chadwick, "The Human Genome Project: Under an International Ethical Microscope" (1994) 265 Science 2035.

⁹⁹ G.J. Meissen & R.L. Berchek, "Intended Use of Predictive Testing by Those at Risk For Huntington Disease" (1987) 26 Am. J. Med. Genet. 283; D.S. Markel, A.B. Young & J.B. Penney, "At-Risk Persons' Attitudes Toward Presymptomatic and Prenatal Testing of Huntington Disease in Michigan" (1987) 26 Am. J. Med. Genet. 295.

¹⁰⁰ D. Craufurd *et al.*, "Uptake of Presymptomatic Testing for Huntington's Disease" (1989) 2:8663 Lancet 603; G.J. Meissen *et al.*, "Predictive Testing for Huntington's Disease with Use of a Linked DNA Marker" (1988) 318 New Engl. J. Med. 535; J. Brandt *et al.*, "Presymptomatic Diagnosis of Delayed-Onset Disease with Linked DNA Markers: The Experience in Huntington's Disease" (1989) 261 J. Am. Med. Assoc. 3108.

¹⁰¹ E. Marshal, "Gene Tests Get Tested" Editorial Comment (1997) 275 Science 782.

troubling that although most adults do not wish to have testing performed on themselves, such requests have frequently been made on behalf of children.¹⁰²

When discussing children's autonomy rights one must also bear in mind that the social and economic ramifications of genetic testing are likely to be far greater in the twenty-first century than they have been in the twentieth century. The reason is that advances in genetic testing and genetic engineering will increasingly be accompanied by "real world" effects in the future. One might say that while the twentieth century gave birth to genetics, the twenty-first century will give it effect. When parents request genetic testing for their children they do so with an understanding of its effects in today's world and are unlikely to understand the consequences that such testing may have on their child in the future. Respect for the child's autonomy rights would allow the "child" to make its own decisions upon reaching adulthood with an understanding of the world as it is then.

C. Mechanisms of Limiting Parental Access to Genetic Information

1. Clinical Judgment of Health Care Professionals

One way of restricting parental access to non-therapeutic genetic testing would be to rely on the clinical judgment of health care professionals. Whenever physicians would hold the opinion that testing would not be in the child's best interests, they could simply refuse to acquiesce to parental requests for testing. This regulatory mechanism would depend on the recognition that health-care professionals have a right, or perhaps even a legal obligation, to refuse to provide medical interventions that in their *bona fide* clinical judgment would be contrary to the best interests of their patient, especially when the patient is a minor.

a. The Right of Health Care Providers to Refuse Demands for Inappropriate Treatment

Health care professionals are not legally obliged to provide medically futile interventions merely to satisfy the autonomy rights of consenting patients.¹⁰³ Critics of the concept of medical futility have argued that it "confounds morally distinct cases: demand for treatment unlikely to work, and demand for effective treatment supporting a controversial end."¹⁰⁴ As a result, some authorities have suggested that medical futility should only be understood as comprising the former demand category, namely de-

¹⁰² M. Morris *et al.*, "Adoption and Genetic Prediction for Huntington's Disease" (1988) 2:8619 *Lancet* 1069; M.J. Morris *et al.*, "Problems in Genetic Prediction for Huntington's Disease" (1989) 2:8663 *Lancet* 601 at 601.

¹⁰³ Pieard & Robertson, *supra* note 76.

¹⁰⁴ C. Weijer *et al.*, "Bioethics for Clinicians: 16. Dealing with Demands for Inappropriate Treatment" (1998) 159 *C. Med. Assoc. J.* 817 at 818.

mand for ineffective treatment, such as the demand for an antibiotic to treat a common cold.¹⁰⁵

While it remains uncontested that physicians are under no legal obligation to provide ineffective treatment,¹⁰⁶ the legal position regarding effective treatment supporting a controversial end is less clear. This issue is significant given that most genetic interventions are likely to fall within the latter category since they cannot be withheld on the basis of being ineffective. The health care professional's right to refuse demands for effective yet inappropriate treatment will have to be hinged on something other than the ineffectiveness or futility of the treatment.

British courts have consistently held that the consent of a functionally competent patient by itself does not impose upon health care providers the legal obligation to provide treatment that is inconsistent with their own professional judgment.¹⁰⁷ Although Canadian jurisprudence is relatively sparse on this issue, there is evidence that the British view is also a correct expression of the law in Canada. In *Ney*, the Supreme Court of British Columbia applied the leading British case of *Re R.*, quoting the passage in which Lord Donaldson held:

It is trite law that in general a doctor is not entitled to treat a patient without the consent of someone who is authorized to give that consent. ... However consent by itself creates no obligation to treat. It is merely a key which unlocks a door. ... *No doctor can be required to treat a child, whether by the court in the exercise of its wardship jurisdiction, by the parents, by the child or anyone else. The decision whether to treat is dependent upon an exercise upon his own professional judgment ...*¹⁰⁸

If health care professionals are not legally obliged to provide treatments that are inconsistent with their own professional judgment, then parental requests for non-therapeutic genetic interventions—interventions that do not offer the child immediate therapeutic benefits in addition to being associated with the risk of harm—might be denied on this basis. The right of physicians to refuse to provide interventions that are inconsistent with their own professional judgment is not without philosophical foundation. As one authority has argued, to force physicians to perform medical interventions which they feel are contra-indicated would be to negate their right to conduct

¹⁰⁵ Canada, *Report of the Special Senate Committee on Euthanasia and Assisted Suicide: Of Life and Death* (Ottawa: Supply and Services Canada, 1995) at 45.

¹⁰⁶ Picard & Robertson, *supra* note 76. See also R.D. Truog, A.S. Brett & J. Frader, "The Problem with Futility" (1992) 326 *New Engl. J. Med.* 1560.

¹⁰⁷ *Re R. (a minor) (wardship: medical treatment)*, [1991] 4 All E.R. 177 (C.A.) [hereinafter *Re R.*]; *Re J. (a minor) (wardship: medical treatment)*, [1990] 3 All E.R. 930, 2 W.L.R. (140) (C.A.); *Re J. (a minor) (wardship: medical treatment)*, [1992] 4 All E.R. 614, 3 W.L.R. 507 (C.A.).

¹⁰⁸ *Ney*, *supra* note 74 at 56-57 [emphasis added].

themselves according to their own moral code or value system and would obviate their autonomy rights in favor of the autonomy rights of consenting patients.¹⁰⁹

A difficulty with this regulatory mechanism is that, since professional judgment regarding the appropriateness of treatment is likely to vary, it would result in a heterogeneous application of the therapeutic-benefit test. Parents would simply have to visit enough health care providers until they found one that was willing to comply with their request for testing. This mechanism could also open itself up to abuse as some physicians may not be fully aware of the potential harms of testing to the child and may be willing to conduct any genetic test so long as the price is right.

b. The Legal Obligation of Health Care Providers to Refuse Demands for Inappropriate Treatment

Another approach would be to say that health care providers have a legal obligation to refuse demands for inappropriate treatment. According to this approach, health care providers who do accede to requests for treatment that they know, or ought to know, is contra-indicated "may be held liable for any injury which the patient suffers as a result of the treatment."¹¹⁰

While an extensive examination of the application of negligence law to the provision of non-therapeutic genetic interventions is beyond the scope of this paper, a preliminary analysis of some of the issues that are likely to arise will be presented.¹¹¹ It should be noted from the outset that the traditional objective of negligence law, namely the *ex post facto* compensation of victims who suffered physical injuries or property damage as a result of the fault of another, is largely incongruent with the primary objective of adopting a precautionary approach towards behavioural genetics, namely the prospective anticipation and subsequent reduction of the immediate and cumulative risks associated with non-therapeutic genetic interventions in order to prevent social, psychological and economic injuries before they occur. Unfortunately,

¹⁰⁹ See A.S. Brett & L.B. McCullough, "When Patients Request Specific Interventions: Defining the Limits of the Physician's Obligation" (1986) 315 *New Engl. J. Med.* 1347 at 1349 [emphasis added], where the authors noted that

[i]f a competent patient refuses to comply with a recommended intervention, the physician has not acted contrary to his or her own moral principles but has merely failed to convince the patient to undergo the intervention. However, if the physician facilitates the patient's request for an unnecessary or harmful intervention to satisfy a principle of respect for patient autonomy, the action reciprocally *undermines the physician's autonomy*.

See also T.E. Quill & C.K. Cassel, "Nonabandonment: A Central Obligation for Physicians" (1995) 122 *Ann. Intern. Med.* 368.

¹¹⁰ Picard & Robertson, *supra* note 76 at 265.

¹¹¹ The possibility of applying fiduciary law to the provision of non-therapeutic genetic interventions will not be dealt with in this paper.

this incongruence leads to many difficulties when it comes to applying the law of negligence to the arena of behavioural genetics.

Difficulties arise in nearly every component of the negligence formula including the standard of care, causation, and injury components. The injury component can be used as an example. While some genetic interventions such as genetic manipulation carry with them the potential of causing physical insult, most of the interventions are associated with the risk of unorthodox injuries such as social, psychological, and/or economic harm to both the individual user and to society as a whole. For instance, an individual whose parents had him tested for Huntington's disease, a late-onset monogenic illness, when he was a child might suffer psychologically from the knowledge that he will develop the disease at mid-life. Given the nature of the injury, however, it is unlikely that a course of action would be available to the plaintiff under our current law. Reticent of the danger of an ever-widening circle of plaintiffs, courts have distinguished between emotional distress and nervous shock, and have only been prepared to award damages in the latter case.¹¹²

An individual whose genetic read-out predicts that she is predisposed to developing both alcoholism and criminality might suffer economic loss as a result of being discriminated against by employers who might prefer to employ a more "genetically conservative" candidate. While it is clear that a valid legal claim of discrimination could be brought against the employer, could the individual also pursue the health care facility for having provided the non-therapeutic genetic testing and/or her parents for having requested such testing in the first place?¹¹³ Once again, given the nature of the injury, it is unlikely that a course of action would be available to the plaintiff under the current law of negligence. The circumstances in which tort law will accommodate claims based on a purely economic loss¹¹⁴ have been greatly restricted by courts that have traditionally been and continue to be fearful of indeterminate and unlimited liability.¹¹⁵

As was noted from the outset, the adoption of a corrective justice system such as the law of torts is an inappropriate means of dealing with an issue whose successful resolution depends on the prevention of harm before it occurs. The *quia timet* injunc-

¹¹² As was stated by Lord Bridge in *McLoughlin v. O'Brian*, [1982] 2 All E.R. 298 at 311, "The first hurdle which a plaintiff must surmount is to establish that he is suffering not merely grief, distress or any other normal emotion but a positive psychiatric illness." See also V. Harpwood, *Principles of Tort Law*, 3d ed. (London: Cavendish, 1997) at 43-45; W.V.H. Rogers, ed., *Winfield & Jolowicz on Tort*, 15th ed. (London: Sweet & Maxwell, 1998) at 159-70.

¹¹³ At present, parents are virtually immune from prosecution for the negligent decisions they make concerning the fetus before it is born. Therefore, should testing occur prenatally, it is unlikely that a successful case could be made against the parents. See *Winnipeg Child and Family Services (Northwest Area) v. G(D.F.)*, [1997] 3 S.C.R. 925, 121 Man. R. (2d) 241; *Dobson (Litigation Guardian of) v. Dobson*, [1999] 2 S.C.R. 753, 174 D.L.R. (4th) 1.

¹¹⁴ A claim where an individual who has suffered neither personal injury nor property damage asserting that another's negligence has resulted in his or her financial detriment.

¹¹⁵ L.N. Klar, *Tort Law*, 2d ed. (Toronto: Carswell, 1996) at 171-219.

tion, an injunction whose issuance does not require that a tort already be committed, is probably the most preventative legal intervention that our private law has to offer. It would of course be absurd to suggest a fetus or small child could avail him/herself of this remedy in order to avoid being subjected to non-therapeutic genetic interventions. What is instead required is a legislative moratorium on the clinical application of non-therapeutic genetic interventions to minors.¹¹⁶

2. Legislation

An alternative to leaving physicians with the difficult and legally uncertain job of making case-by-case assessments would be to enact legislation.¹¹⁷ Legislation could be used to circumscribe parental access to only those genetic tests offering immediate medical benefits to the minor. Access to non-therapeutic testing would be denied.

Such legislation would have to address the issue of the minor's personal right of access to genetic interventions. That is, it would have to address whether the right of access should be deferred until the minor has attained the legal age of majority (age based) or whether it should be deferred until the minor has developed the capacity to consent to testing for him/herself (capacity based). This issue is significant given that many requests for genetic testing are currently being made by adolescent minors in the absence of their parents.¹¹⁸

The International Huntington's Association and World Federation of Neurologists' policy statement recommends that testing only be available to persons having reached the age of majority.¹¹⁹ However, this policy statement as well as most of the debate surrounding Huntington's predictive testing has been centered on the situation where parents are requesting testing for their young child and not on the scenario where competent adolescents are requesting testing for themselves.¹²⁰

Premising the right of access to genetic testing on the age of majority would be inconsistent with both Canadian case law and with the emerging recognition that adolescents can make informed choices about their health. According to Canadian case law, if a minor is capable of understanding the nature and purpose of a given treatment as well as the consequences of giving or refusing consent to that treatment,

¹¹⁶ Behavioural genetic research would not be subjected to the moratorium. See *e.g.* D.C. Wertz, "Leave the Door Open to Research" (1994) 13:2 *Politics & Life Sci.* 235.

¹¹⁷ Some countries, such as France and Norway, have already begun to incorporate "therapeutic" criteria into their legislation to curtail the use of genetic tests for sex selection and trait enhancement. See Knoppers & Chadwick, *supra* note 98.

¹¹⁸ European Community Huntington's Disease Collaborative Study Group, "Ethical and Social Issues in Presymptomatic Testing for Huntington's Disease: A European Community Collaborative Study" (1993) 30 *J. Med. Genet.* 1028.

¹¹⁹ "Predictive Test in Huntington's Disease", *supra* note 64.

¹²⁰ M. Bloch & M.R. Hayden, "Opinion: Predictive Testing for Huntington Disease in Childhood: Challenges and Implications" (1990) 46 *Am. J. Hum. Genet.* 1; M.Z. Pelias, "Duty to Disclose in Medical Genetics: A Legal Perspective" (1991) 39 *Am. J. Med. Genet.* 347.

then that minor's consent is valid in law.¹²¹ Moreover, "the age of the child is simply one of many factors that must be taken into consideration. The age, intelligence and experience of the particular child must be considered, along with the nature and consequences of the particular treatment. Thus, capacity may vary among children of the same age."¹²² Further, the responsibility for determining a minor's capacity rests with the physician who is seeking the informed consent.¹²³ Thus, as a matter of law, there is substantial precedent for the view that adolescent minors should have access to genetic interventions once they have developed the capacity to consent.

There is also a growing consensus that, as a matter of ethics, adolescent minors should be entitled to consent to their own health care once they have developed the capacity to consent.¹²⁴ The reason for according greater ethical weight to the health care decisions of capable adolescent minors is that their decision-making approximates that of adult decision-making and is therefore entitled to more deference. Moreover, empirical evidence from disciplines such as developmental psychology and

¹²¹ *Johnston v. Wellesley Hospital* [1970] 2 O.R. 103, 17 D.L.R. (3d) 139 (H.C.J.); *C. (J.S.) v. Wren* (1986), 76 A.R. 115, [1987] 2 W.W.R. 669 (C.A.); *Re Y. (A.)* (1993), 111 Nfld. & P.E.I.R. 91, [1993] N.J. No. 197, online: QL (NJ) (Nfld. Unif. Fam. Ct.); *Walker*, *supra* note 79; *Ney*, *supra* note 74. Capable minors can also consent to medical treatment in England, see *Gillick v. West Norfolk and Wisbech Area Health Authority*, [1985] 3 All E.R. 402, [1986] Crim. L.R. 113 (H.L.). In addition to case law, provincial legislation has been enacted in several provinces in an effort to clarify when and how minors may give informed consent to medical treatment. Whereas legislation in some provinces such as Ontario is a reflection of the common-law rule (consent based on capacity), legislation in other provinces such as Quebec is age-based. However, even in the case of age-based legislation, the age at which minors can give their consent to treatment is well below the age of majority. For instance, in Quebec the general age at which minors can consent to care, even care not required by their state of health, is 14 (arts. 14 and 17 *Civil Code of Québec*—However, parental consent will be required if there is a risk that the treatment may cause "grave" and "permanent" effects).

¹²² McCall & Robertson, *supra* note 82 at 165-66; M.L. McCall & G.B. Robertson, "The Common Law Jurisdictions" in B.M. Knoppers, ed., *Canadian Child Health Law: Health Rights and Risks of Children* (Toronto: Thompson Educational, 1994) 151 at 165-66.

¹²³ L.E. Rozovsky & F.A. Rozovsky, *The Canadian Law of Consent to Treatment* (Toronto: Butterworths, 1990) at 56.

¹²⁴ Committee on Bioethics, "Informed Consent, Parental Permission, and Assent in Pediatric Practice" (1995) 95 *Pedia.* 314; R.H. Nicholson, *Medical Research with Children: Ethics, Law, and Practice* (Oxford: Oxford University Press, 1986) at 149; D.W. Brock, "Children's Competence for Health Care Decision-making" in L.M. Kopelman & J.C. Moskop, eds., *Children and Health Care: Moral and Social Issues* (Boston: Kluwer Academic, 1989) 181 at 183; Group for the Advancement of Psychiatry, Committee on Child Psychiatry, *How Old is Old Enough? The Ages of Rights and Responsibilities* (New York: Brunner/Mazel, 1989) at 67, 70; A. Lynch, "Research Involving Adolescents: Are They Ethically Competent to Consent/Refuse on Their Own?" in G. Koren, ed., *Textbook of Ethics in Pediatric Research* (Malabar, Fla.: Krieger, 1993) 125 at 127-28; L.A. Weithorn & D.G. Scherer, "Children's Involvement in Research Participation Decisions: Psychological Considerations" in M.A. Grodin & L.H. Glantz, eds., *Children as Research Subjects: Science, Ethics, and Law* (New York: Oxford University Press, 1994) 133 at 154.

psychiatry supports the view that adolescent decision-making can often approximate that of adults.¹²⁵

Therefore, as a matter of law and ethics, if legislation is chosen as a means of limiting parental access to non-therapeutic testing, such legislation should defer the minor's personal right of access to genetic testing until such time that the minor has developed the capacity to consent to testing for him/herself.

Conclusion

In the twenty-first century, policymakers and regulators will have the important and exceedingly difficult task of defining the acceptable limits of the intrusion of science upon society. As advances in genetic testing and genetic engineering are increasingly accompanied by "real world" effects, decision makers will be forced to grapple with the issue of the law's role in regulating genetic technology. This will be no simple task:

Our lives would be easier if, for example, it were true that complex human behaviours in principle could not be manipulated by genetic means. We would not need to worry about the extent to which we ought to engage in such manipulation because such manipulation would be impossible. Likewise, our lives would be easier if it were true that genetic information about complex behaviours were inherently dangerous. We could then be spared the difficult work of distinguishing between hurtful and helpful uses of it.¹²⁶

The recommendation put forward in this paper is that, for the time being, genetic technology should only be made available to society in circumstances where it offers immediate therapeutic benefits of proven efficacy as well as a positive benefit-risk ratio. This recommendation is premised on the precautionary principle requiring that action be taken to avoid risks *in advance* of certainty about their nature.¹²⁷

The potential impact of behavioural genetics on the future, apart from the clear benefits that will accrue from preventing serious disease, is not necessarily to be welcomed. Proceeding in a slow, step-by-step, incremental fashion is the most desirable approach. We must not view each advancement in isolation. Most importantly, we must not lose sight of the cumulative effects of today's decisions on tomorrow's society. That is, genetic technology should only be permitted to intrude upon society in those limited circumstances where there is substantial evidence that the intrusion would be beneficial. Absent such empirical evidence, such as in the case of non-

¹²⁵ L.A. Weithorn & S.B. Campbell, "The Competency of Children and Adolescents to Make Informed Treatment Decisions" (1982) 53 *Child Devel.* 1589; R. Abramovitch et al., "Children's Capacity to Consent to Participation in Psychological Research: Empirical Findings" (1991) 62 *Child Devel.* 1110; N. Ondrusek et al., "Empirical Examination of the Ability of Children to Consent to Clinical Research" (1998) 24 *J. Med. Ethics* 158; C.C. Lewis, "A Comparison of Minor's and Adults' Pregnancy Decisions" (1980) 50 *Am. J. Orthopsychiatry* 446.

¹²⁶ Parens, *supra* note 44 at 17.

¹²⁷ J. Hughes, "Xenografting: Ethical Issues" (1998) 24 *J. Med. Ethics* 18.

therapeutic genetic testing of children, it is recommended that decision-makers base their regulatory efforts on the precautionary principle in order to avoid the risk of doing serious harm.
