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Children in the moral community.
Predictive genetic testing of children for
adult onset diseases: some ethical
implications

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Abstract

Where are children situated in the moral community? Are children special from a moral point of view? Does children's youth and vulnerability say anything significant about how we ought to treat them? These questions seek to articulate and clarify the moral status of children by considering what is required to be the beneficiary of moral standing, and furthermore, the ways in which we, as moral agents, are obliged to treat them. The ways in which we answer these questions has significant implications for children, particularly in the area of predictive genetic testing.

My thesis is divided into two sections. In the first section I examine the moral status of children within the moral community and the obligations owed to them from parents and society. This is important for a number of significant reasons: Firstly, within the literature children are often portrayed as smaller, less competent versions of adults, yet they are clearly different to adults in many significant ways. Secondly, whilst we claim that children are precious and deserve to be protected from harm, we continue to abuse, neglect, and treat them with indifference in our families and communities. Finally, children grow up and assume their place in the world. This suggests that their moral status changes over time. If children are important members of the moral community as I suggest they are, then we ought to be clear about what their moral status obliges of us as adults. This has crucial implications for children in the area of predictive genetic testing for adult onset diseases.

In section two I build on the ethical framework and conclusions reached in the first section and examine the specific question of whether we ought to genetically test children for adult onset diseases. All international genetic service provider guidelines and professional genetic societies do not recommend testing currently healthy, asymptomatic children for such diseases. I examine their positions and consider the arguments not to test children for adult onset diseases.

Dedication

I would like to dedicate my thesis to my father, Alan Robert Gurr, and to all children and their families living with an adult onset disorder.

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Introduction

Developments in the field of molecular genetics mean that we are increasingly able to detect the genes responsible for hereditary disorders. Some hereditary disorders are detectable at the embryonic stage and may result in an affected embryo not being implanted into the womb (pre-implantation genetic diagnosis). Some disorders are detected during pregnancy and may result in a termination at the request of the parent(s). The decision not to implant a particular embryo or to proceed with selective abortion is made on the grounds that to bring an affected child into the world with such a condition would be to visit a serious harm against the child. Some disorders onset during childhood and adolescence and may be detected through genetic testing when the child is young. Some disorders will not develop until adulthood and may be detected during childhood¹. This thesis explores the ethical issues and implications of this latter group of hereditary disorders: that is, testing currently healthy, at-risk children for diseases they may come to develop as adults.

All international genetic service provider guidelines and professional genetic societies advise against testing currently healthy, asymptomatic at-risk children for disorders that will not develop until adulthood unless there are clear medical benefits that have been established as beneficial, should the child test positive for a mutation. These tests are referred to as predictive genetic testing (PGT). Such a prohibitive stance is also defended on the grounds that PGT of children may result in a number of serious harms.

¹ Currently the progression of most adult onset disorders cannot be halted; neither can they be treated or cured. Throughout my thesis I use predictive genetic testing (PGT) for adult onset diseases to mean 'PGT for adult onset diseases which cannot be halted, treated or cured'.

As one of the first maxims of medicine and morality is, '*primum non nocere*' – *first cause no harm*, we must be extremely cautious of any action that may result in harm to others, especially harms to children.

To date, there is no empirical evidence to clearly show that testing children for adult onset diseases will result in serious harms to children, in part because there is a general worldwide prohibition on such testing. In the absence of such empirical evidence we must proceed cautiously with any call to support the testing children for these diseases. However, there is a growing body of medical and bioethical literature that suggests such testing may in fact benefit children in a number of important ways. As many of the difficult and challenging concerns and questions in this area of genetic testing are ethical ones, we must critically and evaluate the arguments both for and against PGT of children for adult onset diseases.

The central question being asked in this thesis is: 'Should we test currently healthy, asymptomatic children for diseases that will not develop until they are adults?' As I have already noted, the fundamental ethical issue here is the concern about serious harms to children. Children are at the heart of this issue, therefore it is important to consider the broader issue of who they are, and what obligations, if any, we as moral agents have towards them. Only when we have considered children in this way can we clearly understand the deeper question of whether we ought to genetically test them for diseases they will not come to develop until adulthood. We must openly, honestly and critically consider the ethical reasons that underlie the prohibition on testing, for these arguments are at the heart of this controversial debate.

Preamble

My philosophical interest in the area of PGT of children for adult onset diseases began in a very personal sense when my father was diagnosed with end stage renal failure as a result of inheriting autosomal dominant polycystic kidney disease (PKD) from his father. The mode of inheritance for PKD is dominant which means that any offspring of an affected individual are at 50% risk of inheriting the disorder. After being diagnosed with PKD some time after my father began dialysis, I began to think about the implications for my young son as he had begun asking if he also had the disorder, and what it might mean for him if he had inherited it. How did I want to answer these questions, knowing as I did that my father's fate possibly lay ahead for him and me?

Currently diagnosis of PKD is by ultrasound imaging (and not a genetic test); however genetic service provider guidelines and professional communities do not support testing children for diseases that will not develop until adulthood (regardless of the type of test available to confirm a genetic mutation). Thus they do not support testing healthy, asymptomatic children for autosomal dominant PKD.

Philosophically I was also interested in the moral status of children, specifically in relation to many of the profoundly troubling and interesting issues and concerns that arise in the field of genetic testing. Although I started thinking about PGT of children for adult onset diseases with an intuition that children are significant and valuable members of the moral community who possess a unique moral status, such an intuition reveals little about why children matter in this particular context, whether we are morally permitted to proceed with testing or not (and if so on what grounds), and whether children should be told certain genetic information (especially where such knowledge may be burdensome for their future)? I was interested in examining that

intuition whilst at the same time considering the practical ethical arguments that arise in PGT; namely whether we ought to genetically test children for these diseases.

As I began to read the medical and bioethical literature I considered the reasons given to justify the prohibitive stance taken in regard to genetically testing children by the various international guidelines and protocols. Not only was it argued that there were few, if any, medical benefits established as effective if children were found to carry a genetic mutation after being tested, but that such testing may result in children being seriously harmed. The reasons given not to test children fell into three specific categories of serious harm:

- Violation of future autonomous choice. If children were tested before they were able to give their informed consent, they could never make an informed choice not to know as an adult. Not testing children respected their future autonomous capacities (namely; their right not to know).
- Risk of invidious discrimination if genetic information is known about an individual specifically in the areas of insurance (life, health and disability), employment and access to healthcare. Individuals who had been tested as children may find it very difficult to secure insurance or employment if they are known to carry certain genetic mutations.
- Risk of psychological harm if children are tested. Some children may feel worthless or doomed with certain genetic knowledge gained through a genetic test result. The family dynamic may be adversely affected; children may lose their self esteem, or face stigmatization within the family and in society (viewed as unmarriageable or unworthy as a friend). There was also a concern that the

risk of suicide may increase for some individuals carrying particularly serious hereditary disorders such as Huntington's disease.

To be honest I wasn't sure what I thought was right in relation to testing children for diseases that would not onset until they were adults. There seemed to be clear and apparently persuasive arguments to support a prohibitive stance (current policy) on testing children and such positions were widely expressed in the medical, legal and bioethical literature. However I felt there were equally compelling reasons to consider requests to test some children. Much of the literature focused on answering the question, 'what harms may eventuate if children are tested for these diseases'; seldom did anyone ask, 'what harms may eventuate if children are not tested?' The putative benefits to children and their families were seldom seriously considered; or if they were contemplated, were generally rejected on the grounds that the harms to children from testing outweighed any so-called benefits. Ironically the literature recognised that there was very little empirical evidence supporting the harms that are alleged to occur as a result of testing and so support current policy.

I also wondered if perhaps we ought to just leave 'children to be children' for as long as possible without imposing certain knowledge on them that could never be unknown. Why get them tested when nothing could be done to prevent the disease from developing later, or to successfully treat them once symptoms began to appear? Why not just let them grow up without the burden of knowledge? I believed it was an area that demanded critical reflection and deliberation, not the least because there seemed to be a number of assumptions made about children and childhood that needed to be explored in the broader context of genetic information and disclosure.

For instance, the autonomy argument is very influential and dominates the (genetic testing) literature for it seeks to protect children's developing self determining capabilities. Morality demands that we respect the autonomy of others, and for those who are not autonomous, or not yet autonomous, the demands are high: we have an obligation to protect those individuals from actions or omissions that may result in serious harm to their developing autonomy. As testing purportedly violates the child's future autonomous choices (as an adult), the principle of respect for autonomy, *prima facie*, supports a ban on testing. But autonomy is not something one suddenly acquires at a certain age; it develops and matures with experience, responsibility and practice. We learn to make autonomous choices in our dealings with others through being encouraged to accept the consequences of our own actions and by learning from the actions of others (role models). Thus, like most of the abilities and capacities we come to develop as adults and exercise in our daily lives, autonomy requires cultivation and support.

The literature assumed that testing children for adult onset diseases violated their future autonomy by limiting the choices available to them as autonomous adults, but the more I read and thought about this justification not to test children, the more certain I became that it wasn't entirely convincing and needed further clarification. Quite simply, the principle of autonomy provoked a number of questions and concerns that were not being addressed or discussed in the literature in any critical way. This is a serious concern because the autonomy issue dominates the literature and principally grounds the practice not to test children. If there are strong reasons to suspect the autonomy argument is not robust, then we must be rigorous in clarifying where it fails: a point which has significant implications for the testing of children.

As the arguments in the literature became clearer to me and I began to see links between commentators and the various reasons put forward for a particular position, I felt strongly that the ethical reasons given to justify not testing children for adult onset diseases were not fully or convincingly explicated. Whilst I respected the cautious approach expressed by many individuals and groups (in light of the dearth of empirical evidence), I was generally dissatisfied with the ethical arguments put forward to defend a prohibitive stance on testing. I felt strongly that if parents² were prevented from having their children tested, and children's requests for testing were ignored, then the reasons defending such a stance ought to be compelling and persuasive. This is because we generally assume it is right to allow parents wide latitude in the upbringing of their children. They know them better than anyone else, and generally have their best interests at heart. If we are to deny parents' and children's requests for PGT, we must be sure the arguments are persuasive. Instead I felt they were unconvincing and rather inadequate.

So I began my thesis preparation with the intention of critically examining the arguments given not to genetically test children for adult onset diseases. It was also apparent to me that in order to think seriously about the ethical implications of genetically testing children for these diseases, I needed to step back and reflect on the moral status of children generally and not just in the context of PGT. This was for a number of reasons:

First, at the heart of this issue are children themselves. They are relevantly different to adults, but will become adults in time. Neither can we isolate children away from the context of the family environment. This is particularly significant for genetic testing

² For ease of continuity and consistency, I will use the term 'parent' to refer to any adult who is the main caregiver in a child's life.

because a diagnosis and its resulting genetic knowledge, is never solely confined to the individual being tested. Genetic information has implications for all blood relatives and so testing must be interpreted and understood with the broader family interests in mind. It also seemed clear that even though we should be guided by studies focusing on harms to adults in relation to PGT, such conclusions may not be entirely appropriate in relation to children and PGT. The focus must be first and foremost on children. This meant reflecting on why children are important members of the moral community and how we ought to treat them.

Second, central to all the arguments defending a ban on testing were issues of what counts as harming and benefiting, and respecting and not respecting the autonomy of the child. In order to be clear about these issues and any implications that may follow, it requires working out what the moral status of a child is, for only that will ground our obligations to them. In other words, if we support a position that demands something cannot be done to children - or conversely that something ought to be done to children - we must be clear about who children are and why they matter.

Third, as I began to think about current positions on the moral status of children, it was clear that things about the parents and family came in on both sides of the issue. For instance, although some commentators naturally assumed that the child was situated in a family, little or no consideration was given to the role of being a parent and the obligations they have to their own children. Sometimes it was assumed there was a possibility of conflict between the best interests of the child and the interests of the parents, sometimes that parents would or would not have the best interests of their child at heart. I believed it was important to look at what the parental role required of parents

in relation to their children because in the context of PGT, generally parents are the ones requesting testing for their children.

Finally, I felt it was crucial to think carefully about our treatment of children in terms of our obligations to them as a community. What are we obliged to do for children who are not our own? It was clear to me that if I was to think about children in a morally responsible way - in regard to PGT - I needed to be very clear about how we understand children and their lives generally; specifically what kinds of conduct are morally required. The fact that children are part of the wider community – and not just their family's - meant that the discussion would be incomplete without a discussion of everyone's obligations to children. Although the literature does occasionally take note of the fact that children and their families are situated in a wider community, it neglects to consider what obligations the community might have, for example, to provide parents with various kinds of support (in the context of considering likely psychological harms that may result from PGT). Once the moral status of children is clear and the groundwork is laid we can then begin to build on and clarify the issues that arise specifically in the area of PGT.

As a consequence of thinking about children in relation to PGT my thesis is divided into two sections. In section one I discuss the position of children within the moral community, their moral status, and the obligations we have towards them both as parents and as members of the wider community. This lays the theoretical groundwork for the discussion to follow in section two which considers the arguments put forward to defend a prohibitively cautious approach to PGT of children for adult onset diseases. As I noted earlier in this preamble these consist of three main arguments: violation of future autonomous choice, the problem of invidious discrimination, and the

psychological harms that may result as a consequence of testing. In section two of my thesis I address each of these arguments in detail and draw on conclusions reached in the first section, reflecting on what they may mean for children in the area of PGT.

Although the literature sets out many of the ethical problems and concerns that are raised in this area, my thesis brings them together for the first time, critically drawing on what it is that is morally significant about children, and the obligations we have to them. The discussion in section one provides a powerful set of tools for dissecting the ethical issues that confront us in the area of testing children for adult onset diseases and offers a framework for addressing and responding to the challenges of genetic knowledge, or indeed in other areas where there is an ethical question about disclosing certain knowledge to children.

Although we were once all children it is easy to forget what it is to be a child in a world in which adults make all (or most) of the decisions concerning children's lives. When we contemplate where children stand in the moral community we must question what is owed to them, what our duties are as parents and as a society and how we ought to treat them. In essence we owe it to children to make clear why they are important and on what grounds we owe them the demanding obligations that I suggest are their due.

Aim of thesis

The aim of my thesis is to present a reasoned and critical discussion of the ethical implications of genetically testing children for adult onset diseases, and whether a prohibitive stance of not testing is justified in light of their position within the moral community and our obligations to them.

Section 1 Introduction

Children in the moral community

“There is now a greater recognition that the moral and political status of children merits extended treatment. Feminist critics of the history of ideas often complain that women have been written out of the story: they simply do not make an appearance or are merely assimilated into the household whose head is male. Much of the same complaint can be made on behalf of children” (Archard, 2003b p xi).

Background

I begin with the intuition that children are special members of the moral community deserving of certain kinds of treatment that we generally do not extend to those who are not children. That is, children possess unique moral status that obliges us as moral agents to treat them in certain kinds of ways. Such an intuition doesn't appear particularly contentious. Most of us would agree for instance, that we are morally obliged to treat children differently from the ways in which we treat adults simply because the needs and interests of both children and adults differ in relevant and significant ways. In fact morality seems to require special treatment towards children. For instance, we are justified in acting paternalistically towards young children to protect them from harm as they are vulnerable to the actions of others and themselves. As such, parents are bestowed extensive but not absolute authority over their children grounded on the notion that the decisions they make for, and on behalf of, their children are in the best interests of the child.

Parents also know their own children better than anyone else. Of course one may question the degree to which decisions ought to be made in the child's best interest. For instance, if there are several children, whose interests prevail; and to what extent can

parents and designated guardians count their own interests (or the interests of the family as a whole) in the equation? Generally though, we recognise and respect parents' decision-making capacities and the way familial and individual interests are calculated.

It may be obvious that children are special members of the moral community and therefore we have certain obligations to them and one could reasonably claim that the fact that we fulfill them is all that matters. Furthermore one might question the relevance of stating what appears to be the obvious: 'we have obligations to children – so what?' There are several reasons why I believe we ought to be clear about why children are special and more importantly, the moral obligations we have to them:

In the world today, millions of children suffer from malnutrition, high mortality rates, extreme poverty, abuse and neglect. In New Zealand and around the world, many children still live in extreme poverty, many suffer from preventable diseases, and many more are abused and neglected by their families and communities. Clearly many children do not receive what is owed to them. If we really believed that our moral obligations towards children were self evident and obvious, and that those obligations ought to be fulfilled, perhaps we would see a reduction in these appalling figures over time. In fact it appears that the plight of many of the world's children, in a majority of the world's developed economies is getting worse (UNICEF, 2005).

Generally all individuals agree that we have obvious obligations to our own children but are less willing to admit that we have extensive obligations to all children (regardless of who they belong to). Examining why we have obvious obligations to our own children makes clear, I suggest, why we also have moral obligations to children who are not our own.

By examining why we have demanding moral obligations to children we emphasize the importance not only of why we ought to treat them in certain ways but the value of children overall. When we are clear about why we have obligations to children and something of what they may entail, we will gain a deeper understanding of why children matter. If we don't examine the basis of those obligations we are in danger of making mistakes in how we treat them, or of dismissing their lives as insignificant. By attempting to understand children's lives as uniquely valuable we place greater significance on the importance of their lives, not only within their own families but also in society generally.

Finally, even though many parents love their children and may claim they do not need to be told what they are obliged to do for them - because they love them - I suggest that it is good to be reminded of children's unique moral status and why we have the obligations to them that we do. This is because love waxes and wanes and sometimes we may not have as much love as we should: thus parents ought to be (gently) reminded of why they do what they do for their children, or indeed, why they ought to do more.

Traditionally, philosophers haven't much cared about children or the lives they lead. Although philosophers such as Plato, Locke, Rousseau and Mill wrote about how children ought to be raised, they did not write on the significance of children *qua* children. Perhaps this was due more to an assumption about the relative insignificance of children's lives (compared to the lives of men) than any attempt to purposely exclude them from moral consideration. Or there may be some truth to the claim that "*many of the great philosophers since antiquity have been rather solitary and childless people*" (O. O'Neill & Ruddick, 1979 p 3).

More recently many contemporary philosophers have considered the character and importance of children and their standing in the moral community (Freeman, 1997), (Archard & Macleod, 2002), (Brennan & Noggle, 1997), (Gaylin & Macklin, 1982), (Macklin, 1982), (Murray, 1996), (Archard, 1993), (Blustein, 1982). However within philosophical discourse generally, children and the lives they lead are still standing in the shadow of adults. A prominent philosophical text has no reference at all to children yet animals and their souls and spirits are accorded extended discussion (Honderich, 1995); and whilst the well known and respected moral philosopher Peter Singer has much to say about our obligations to those in distant places and our duties to non-human animals he has very little to say about children and their place in the moral community.

It is time then to think about children and their position within the moral community.

Chapter Summary of Section One

In chapter one, I examine what the philosophical literature says about children's moral status and the moral obligations we have to children. I then focus on two central accounts that claim our obligations to children are grounded in their moral status as sentient beings; or their moral status is grounded in their moral status as rights-holders. Under the sentience account, we have obligations to children because they are sentient beings that have an interest in avoiding pain and suffering. Under the rights account, we have obligations towards children because they are rights holders who have certain fundamental interests (Interest theory) or can make autonomous choices (Will or Choice theory). I conclude that neither these two accounts, despite their valuable insights, go far enough, nor do they do justice to the complexities and uniqueness of children's lives.

In chapter two I outline what I believe is a plausible and compelling way of looking at why we have the obligations to children that we do. My account claims that children possess unique moral status as a result of four significant features about them:

- They have fundamental needs that are crucial for their well being
- They are vulnerable
- They belong to us (they are ‘ours’)
- They are the future

Whilst there are many adults in society who are also characterised by some of these features, I suggest only children possess all four and as such have unique moral status. My account of why we have the demanding obligations to children that we do offers a different way of thinking about them that both recognises their uniqueness within society and at the same time their similarities with others. It is precisely because they are understood in this way that we have the obligations to them that we do. We do not have the same obligations to, or hopes for, any other group in society in quite the same way.

In chapter three I consider the role of parents and the obligations they have to their own children. I also propose and examine the claim that central to the role of being a parent is the obligation to nurture and facilitate the child’s developing autonomy. The parental role is demanding and crucial not only to ensure the flourishing and well being of children but also the good health of society generally.

I claim in the fourth chapter that parents cannot and indeed ought not to be the only individuals obliged to fulfill a number of obligations to children. This is because we all have an interest in the well being and flourishing of children generally, and so their

lives are also a community's responsibility and concern. I also focus on the importance of the notion of impartiality in explicating our obligations to children who are not our own.

In the final chapter I reflect on some of the conclusions I have begun to make in my discussion as I focus on a practical issue that arises in the context of parenting. If children are special members of the moral community and if, as I suggest in chapter three, the role of parenting is demanding in terms of the obligations that are owed to them then ought we to consider licensing individuals before they become parents? In this chapter, I begin the discussion by briefly giving some background to the issue of licensing individuals and then I consider the notion of serious harm that Hugh LaFollette employs. LaFollette focuses exclusively on the serious harms to children that result from physical abuse, neglect and maltreatment; however I claim that moral consistency demands we broaden our awareness of what constitutes serious harm.

I reflect on the serious harms children suffer from three different perspectives: growing up obese, living in a smoky environment and being raised in poverty. In all cases I suggest that the harms children suffer as a direct result of living in such circumstances are serious. Although one may claim that this strengthens LaFollette's claim - that is, it provides further justification to license individuals before they become parents, I argue that the practical consequences of such a licensing program will result in *far* greater harm not only to potential parents, but those who are already parents and to the children themselves.

Finally I suggest some alternatives to licensing. I conclude that a licensing program such as LaFollette's is morally impermissible. However this is not to suggest that we ought not to seek ways to reduce and ameliorate the serious harms that are done to

children. As parents and adults we have an obligation to protect all children from serious harm.

Finally, I draw together the conclusions reached in section one and reflect on where children stand in the moral community. This 'ethical groundwork' lays the foundation for the discussion to follow in section two.

Chapter 1: Children's moral status and the moral obligations owed to them

Introduction

Determining who or what has moral status is crucial if we, as moral agents, are to act in morally appropriate ways towards them. This is because to possess moral status is to be worthy of moral consideration which may require that others have certain obligations to us.

In the introduction I began with an intuition that children are special members of the moral community who possess unique moral status which in turn obliges others to act in certain ways towards them. An examination of the basis of an entity's moral status has profound implications for the obligations owed to them, and the ways in which others are obliged to act in relation to them. Therefore it is important to clearly examine the basis of children's moral status.

Although a great deal has been written in the philosophical literature about what grounds our obligations to others generally, very little has been said about what grounds our obligations to children; and what has been said is more or less inadequate to account for them.

In this chapter I will examine what some philosophers are committed to about children's moral status from two different accounts:

- That our obligations to children are grounded in their moral status as sentient beings
- That our obligations to children are grounded in their moral status as rights-holders

Before I begin however, it will be necessary to clarify the term ‘children’ as I shall be using it and the important relation between the concepts of ‘moral status’ and ‘moral obligation’.

Clarifying the term ‘children’

Essentially children are characterised by their lack of or limited cognitive abilities³, their powerlessness and their overwhelming dependence on the adults around them for almost all their needs. They are generally viewed as vulnerable to the actions of others, and innocent of moral wrongdoing. Understanding children in this way also clearly encompasses those adults who for one reason or another are considered childlike (for example, those adults who have the ‘mental-age-of-a-five-year-old’).

In many respects it is problematical to point to a specific year and claim that all individuals below this point are still children and those immediately above are (young) adults. We know that many thirteen and fourteen year olds are competent and informed sufficiently in some situations to make autonomous decisions about their own lives, and likewise, that some individuals considered adult, fail in this regard. We also recognise that whilst many adolescents may not be capable of giving informed consent, or of fully understanding the implications of some situations, respect for their developing

³ These include: to be able to reason, limited ability in determining their own interests either now or in the immediate future, limited self awareness, inability to rationally determine one’s own life and awareness of the self as a continuing entity, limited experience of the world and one’s place in it, limited autonomy; an inability to see the connection between cause and effect.

autonomy demands that we at least seek their assent when making important decisions on their behalf. It is essential that we recognise and are sympathetic to their views about matters of importance that involve them (how they see themselves in the world).

However it is necessary to fix some point of reference whereby we can reasonably and confidently say that all those who fall below this standard ought to be considered as children and those above should not. Although the end of childhood is generally acknowledged as eighteen years of age, my discussion focuses primarily on children assumed to be below the age of thirteen years because it is during this period that we can more clearly see children's dependency (on adults) and their general lack of autonomous capabilities and cognitive abilities.

I suggest that when we use the term 'children', we are in fact not referring to adolescents, or at least we should not be. Whilst there will be some children who have cognitive abilities that are equivalent to or surpass those of adolescents and adults, the characteristics I have outlined are generally true of children.

Furthermore it would be misleading to characterize childhood solely as a condition typified by what the child lacks. As Archard points out, "*the child is incomplete but open to completion*" (Archard, 2003a p 93). Whilst children do lack many of the features that characterize adulthood, they do not remain children forever. Thinking of childhood in this way – as a stage of development that children pass through – has important implications for how they are viewed as moral beings and the obligations we have to them. In fact at the heart of 'childhood' lies the obvious truth that (almost) all who enter childhood leave at some point in the future.

Moral status and moral obligations

According to Warren, “*To have moral status is to be morally considerable, or to have moral standing. It is to be an entity towards which moral agents have or can have moral obligations. If an entity has moral status, then we may not treat it in just any way we please; we are morally obliged to give weight in our deliberations to its needs, interests or well being. Furthermore, we are morally obliged to do this not merely because protecting it may benefit ourselves or other persons, **but because its needs have moral importance in their own right***”⁴ (Warren, 1997 p 3).

Something has moral status because it counts in morally significant ways; it is valuable in its own right and cannot be reduced to its usefulness to others. You simply cannot treat it how you please without regard for its inherent worthiness. If a thing does not have moral status then we can treat it how we please, as long as this does not involve failing to fulfil an obligation to something that does have moral status⁵ (indirect duties).

When we are thinking about who or what has moral status, we need to ask the question, “*what sorts of things are such that their continued existence or welfare is valuable in themselves?*” (Pierce & vanDe Veer, 1995 p 21). Or to put it another way, ‘what kinds of properties or features count in morally important ways?’ Traditionally one view claimed moral status was reserved only for those beings that were human. So in answer to the question, ‘who or what has moral status?’, the response would be, “*all and only human beings have moral standing*” (*Ibid.*, p 7). Human needs, interests and well being were all that needed to be taken into account when determining moral standing.

⁴ Bold is my emphasis

⁵ Although my car does not have moral status, you may not treat it how you please. Your obligation not to harm me (as an entity with moral status) extends to you not interfering with my car without my permission.

More recently, commentators in the fields of environmental and animals ethics reject the view that to be the recipient of moral standing one only has to be human (Singer, 1975, 1993b), (Regan, 2004), (Regan & Singer, 1989), (Schweitzer, 1987), (P. Taylor, 1981, 1986). It has been suggested that any criterion of moral standing must encompass more than simply human beings because many non-human beings have interests and needs similar, if not identical to human beings, and non-human beings may be valuable in ways that transcend their utility to others. Properties that might confer moral status include: personhood, potential personhood, rationality, linguistic capacity, sentience, being alive, being an integral part of an ecosystem, and being an ecosystem (Pierce & vanDe Veer, 1995 p 10).

Recognising an entity's moral status then depends on the importance one places on certain features or characteristics of the entity in question; for instance, are they alive, or sentient, or do they possess linguistic capacities? Two key points are clear: First that the boundary of who, or what possess moral status is contentious (because people disagree about what properties or features should be recognised as morally important), and second, that what grounds moral status becomes much broader if we look beyond traditional views of human intrinsic worth (needs, interests and well being).

Moral obligations are those ties that impinge on a moral agent and require that she do, or is constrained from doing "*something by virtue of a moral rule, a duty, or some other binding demand*" (Honderich, 1995 p 632). If an entity has moral status, we as agents have moral obligations (to them) in respect of their inherent worthiness. But a number of questions arise, 'Are there degrees of moral status: do some entities possess more moral status than others, or do we have the same kinds of moral obligations to all who possess moral standing?' An obvious response is that we do not have the same

obligations to all entity's possessing moral status. I have different kinds of obligations to different entity's even though each has moral status and is intrinsically valuable. So for instance, the obligations I have to my son to ensure his good health and well being differ from any putative obligation I may have to non-human animals to ensure their continued good health, even though both may possess moral status. One may reason that the obligations I ought to fulfill (in respect of the moral status each possesses) come about because of the kind of relationship I have with my son: a relationship that I do not have for instance, to the local domesticated cat population. One may further reason that my obligations to those with moral status differ depending on the cognitive and intellectual capacities of the individual or entity in question. So for instance, I have more demanding obligations to my son because of his cognitive awareness and intellectual abilities than I do to my dog.

My point here is that determining who or what has moral status is important in orienting us to those entity's to which we, as moral agents, have certain obligations and responsibilities. In a sense, recognising the moral status of an entity, indicates *prima facie*, that we have certain duties to them but as I noted above, such recognition is not enough on its own, because simply to possess 'moral status' does not clearly indicate what obligations we may have to them. The list of criteria I noted above (personhood, potential personhood, rationality and so on) give a partial explanation on what constitutes an entity's moral standing but it doesn't take into account other characteristics that I believe are crucial in determining why moral obligations are owed in the first place.

According to the above criteria, children clearly possess moral status, and so according to Warren, we are morally obliged to give weight to their needs, or interests or well

being. But in the literature that is particularly concerned with our obligations to other persons, or to other non-human animals, or to the environment, just what this might entail for children is left very unclear.

In the following discussion I focus on the account of sentience; that our obligations to children are grounded in their moral status as sentient beings.

Sentience and moral status

One account claims that children have moral status because they are sentient beings.

Sentience; the capacity to experience pleasure and pain, defines the boundary of moral status. If a being can experience pleasure and pain then it has interests; the primary interest such a being has is to avoid pain and suffering, thus we have obligations to all sentient beings to minimize as much pain and suffering as possible. Peter Singer is perhaps the most vocal advocate of this account of why obligations are owed to others and not just human beings (Singer, 1993b).

Singer argues that the boundary of moral consideration ought to be drawn around all conscious sentient beings, thus we have clear obligations to all those beings that experience pleasure and pain. His account of sentience is drawn from Jeremy Bentham's view that the capacity for suffering and enjoyment or happiness must be recognised and taken into account. *"If a being suffers, there can be no moral justification for refusing to take that suffering into consideration... If a being is not capable of suffering, or of experiencing enjoyment or happiness, there is nothing to be taken into account. This is why the limit of sentience is the only defensible boundary of concern for the interests of others"* (Ibid., p 57-8).

To be sentient then is to have moral status which *"is to be an entity towards which moral agents have or can have moral obligations"* (Warren, 1997 p 3).

It is this interest in the capacity to feel pleasure and pain, “*that entitles a being to equal consideration*” (Singer, 1993b p 57). In other words, we cannot neglect the pain and suffering of a dog, just because it is a dog and not a human being: the dog also has an interest in its pain being relieved. Failure to recognise the animal’s suffering simply because it is an animal (and not a human being) amounts to speciesism according to Singer (Singer, 1975). However this does not mean we ought to consider the suffering of all beings equally or that there is no relevant moral difference between humans and animals. Not all lives are of equal worth. Some beings have other important capacities which may influence how their suffering ought to be understood and this is a significant point to clarify further because it has serious implications for children.

Capacities such as anticipating the pain and suffering, mental anguish and being frightened of certain consequences mark a distinction (if not a precise one) in deciding how to treat human and non-human sentient beings. “*Normal adult human beings have mental capacities that will, in certain circumstances lead them to suffer more than animals would in the same circumstances*”(Singer, 1993b p 59). So for example, if a certain action would result in the same amount of physical pain to both human and non-human beings, the fact that the human can anticipate the pain and may be extremely fearful of it means that their suffering is worse than the same pain exacted on non-human beings who cannot anticipate it (this does not mean that we are justified in causing it suffering simply because it cannot anticipate, or fails to understand, our (intended) actions).

However, it is also true that whilst we may be able to reassure a human being that their suffering is only temporary and alleviate their fears, we cannot do this for non-human animals and so their pain and suffering may actually be worse because they cannot

understand that the experience is only temporary. The wild animal that is enclosed in a cage so that it can be safely transported elsewhere may experience genuine terror despite the fact that no harm is intended and that being enclosed is for its own protection.

As is well known, Singer is mainly concerned to argue against the pain and suffering we inflict on non-human sentient animals. But what does an account of sentience tell us, if anything, about children's moral status and the many other obligations that are owed to them? Very little it seems.

Children are clearly sentient beings but they lack many of the cognitive capabilities that would give them greater consideration in relation to non-human animals (especially the higher mammals). Thus it would seem (under this account of moral status) that our obligations to young children are no different to the kinds of obligations we have to other conscious sentient non human beings like pigs and dogs. In fact Singer makes reference to this himself in the area of scientific experimentation. He claims that because human infants (and severely intellectually disabled humans) '*have no idea what is happening to them*', (Singer, 1993b p 60), they are situated in the same category as many nonhuman animals. This may also be a reason for preferring to use them in experiments, rather than non-human animals. In fact surely one could claim (consistent with what Singer argues), that it would be preferable to use some defective human children and adults **instead** of some non-human primates and higher mammals? Singer argues that "*if we make a distinction between animals and these humans, how can we do it, other than on the basis of a morally indefensible preference for members of our own species?*" (*Ibid*).

I suggest the implications of Singer's views in regard to our obligations to children as sentient beings and members of the moral community are deeply problematic because such a view fails to recognize important features other than sentience and certain mental capabilities. He claims we have an obligation to prevent or ameliorate the pain and suffering of sentient beings and of course children are included in any such group, but beyond that, what obligations do we have towards children who are clearly sentient and so clearly have moral status? From Singer's account of sentience it would seem we don't have many obligations at all.

I believe this is a serious problem for the view that our obligations to children find their basis in children's moral status as sentient beings. For all we can say with confidence is that children have moral status because they experience pleasure and pain, but for young children, their moral status is equivalent to that of many non-human animals. Such an account does not capture or illuminate why children are special members of the moral community.

In the following discussion I will consider the view that our obligations to children are grounded in their moral status as rights-holders.

Rights and moral obligations

“Rights are important because those who lack rights are like slaves, means to the ends of others, and never sovereigns in their own right” (Freeman, 1997 p 25).

“Those who wish to see the status and lives of children improved must continue the search for the moral foundation of children's rights” (Ibid., p 41).

What are rights and why are they important? Essentially rights are strong moral or legal claims (entitlements) held by individuals. To have a right is to be able to justify acting in a particular way. It may also entail that others not act in a particular way towards me

(non-interference), or that they must do something for me (that is, provide me with something).

Therefore the language of rights is extremely strong because rights shape and underpin not only how we ought to act in relation to one another, but also the workings of our government and the nature of our laws. Nozick claims that individuals have rights, *“and there are things no person or group may do to them (without violating their rights)”* (Nozick, 1974 p ix). It has been suggested that a society without rights would be morally impoverished (Freeman, 1997). Rights, Freeman claims, are a *“necessary precondition to the constitution of humanity, of integrity, of individuality, of personality”* (*Ibid.*, p 25).

Rights are also important because they are a powerful means of protecting human dignity and vulnerability. But are all individuals rights-holders or do rights function to protect certain kinds of individuals? In other words, what is the basis on which an individual is recognised as a rights-holder? There has been spirited debate in the literature over the years about the function of rights: do rights function primarily to protect the autonomous choices individuals make (in which case not everyone is a rights-holder), or do rights function to protect one’s fundamentally important needs and interests (in which case all individuals who possess fundamentally important needs and interests are rights-holders)?

The way in which we answer these questions has important implications for children’s rights and the subsequent obligations owed to them. If rights function primarily to protect the autonomous choices of individuals, then considering young children as rights-holders is highly questionable. This is for a number of reasons:

First, children are generally considered incompetent to make important decisions about their lives because they are not yet capable of autonomous decision-making. They generally do not have the capacity to consider themselves over time and have a limited experience of life from which to judge the soundness or appropriateness of their decisions. As a consequence of their limited, but developing abilities, paternalistic action towards them is generally justified where the good of the child is the primary goal. Where paternalism is justified in our treatment of a child, it appears inconsistent to recognise them as rights-holders at the same time.

Second, as children are generally unable to demand or waive any putative rights they may have because of their vulnerability and dependence on the adults around them recognising them as rights-holders appears problematic. Archard notes that in the view of some theorists, *“the very vulnerabilities and incapacities that seem to ground the moral urgency of children’s claims disqualify them as proper rights bearers”* (Archard & Macleod, 2002 p 5).

Third, ascribing rights to children is controversial because rights language is necessarily individualistic, yet children are generally situated in families where the individualism of rights seems an inappropriate way to regard children’s lives and the obligations owed to them. Rights protect individuals first and foremost. As children are individuals in one sense (they exist physically as such), they are not individuals in the sense that rights generally demand (that of an autonomous agent).

Finally, this theory is grounded in an account of autonomy where the function of such rights is to protect the autonomous choices (or will) of the agent. However agreeing on the boundary of who is included and excluded as rights-holders is notoriously difficult due to differing conceptions of autonomy, especially the changing decision-making

capacities of children. Many children are capable of making important decisions about their lives as well as many adults, although generally young children are not considered competent to make life changing decisions about their lives. Do we then recognise rights for some children (those who can demonstrate autonomous decision-making abilities) and not others (those who cannot demonstrate such abilities)?

The interest theory of rights appears a more promising candidate for children's rights because all children have certain fundamentally important interests. On this account children have moral status because they have important interests, which in turn are protected by rights. So for example, in regard to the child's right to an education, interest theory claims that the child's interest in being educated "*is so important that others are under an enforceable duty to provide*" the child with an education (Archard, 2003b p 5).

One problem with the interest theory in recognising children's rights is this: if children have a fundamental interest in growing up in a loving, secure and nurturing environment, does that translate to children having a right to these things and if it does, what does it mean for children who do not receive these goods? How does a child demand her right to be loved? Does a parent have an obligation to love her child? Understanding love in this way (as a duty one is obliged to fulfil) seems to diminish what is so valuable about being loved – that it cannot be manufactured or called into existence simply by right. If the question, 'why do you love me?' was answered with 'because I have an obligation to', surely we would feel such 'love' was deficient in some significant way. Aside from other fundamental needs and interests such as adequate nutrition, clean air and water, shelter and clothing, it is not clear what fundamental interests, interest theory protects.

If children are recognised as rights-holders under the choice theory of rights it may be because they can have representatives who can enforce or waive the rights on their behalf. However, whereas an adult can demand their rights, even when doing so may not be in their best interest, the child's representative is generally compelled to act in the child's best interests (rather than acting on their choices or will) where rights are concerned. For instance, an adult may demand that their right to refuse medical treatment (even where it will save their life) be respected as they do not wish to continue living. As long as the adult in question was competent to make the decision and was not being coerced by medical staff or family, most reasonable people would agree that her right to withdraw from treatment be respected.

If for the sake of argument children possessed that same right, it seems unlikely that the child's representative would demand that it be enforced (even where the child expressed a deep wish to die). This is because the representative would most likely claim that the treatment will save the child's life and this is in her best interests for several important reasons: the child's lack of life experiences to make such an important decision, her lack of understanding about the permanency of death, and the fact that most young children's preferences change frequently (in other words, she may not want to die tomorrow). But isn't that just the point of rights – we respect them even when the provision of them isn't in ours or others' best interests? In other words, what is important about rights is that they signal something important about our autonomy (our capacity to live our own lives as we so desire). The fact that many children are not autonomous is a valid reason to suppose that recognising rights for them is not always appropriate. Under this account, rights lose their strength and normative importance. What does this mean for children?; where representatives act as advocates for children,

they are really acting in the child's best interests and are not recognising the child's choices.

Furthermore there is a concern about who would be the most appropriate individual to represent children's rights. When the representatives are the child's parents there may be a serious conflict of interests. It is unlikely and perhaps unreasonable to expect a parent to comply with the provision of a child's right when the provision of that right conflicts with the interests or rights of the parents. For instance, a parent may justly claim that they have a right to bring their own child up as they see fit, but this may conflict with the child's claim that they have a right to live the kind of life they wish (and it is not the same as their parents). Although we rightfully infringe family privacy and parental rights when children are abused and neglected an important question remains; 'if parents may not be the best representatives for their own children, who ought to be?'

Arneil claims that recognising children as rights-holders does not improve their lives (Arneil, 2002). Whilst recognising rights for many groups of individuals such as women and blacks has improved their lives, children she argues, are different, both in terms of the "*particular nature of their existence, and the approach the "authorities" (namely their care givers) take to their emerging independence*" (Ibid p 86). Rights talk places the emphasis firmly on autonomy and agency in a liberal society and young children are not autonomous. But the problem is deeper than simply one of agency (or lack thereof). Arneil claims that imperfect obligations such as those created by a child's need for kindness, affection, and attention are inexpressible in the language of rights. Moreover rights talk "*necessarily constructs the family as an association rather than a community, particularly when the need to support and nurture ongoing relations is*

needed by most children” (*Ibid* p 87). Rights talk is necessarily adversarial and competitive.

The very nature of rights talk is one that does not sit easily with children in families. This is because within a family environment focusing on the rights of the individual members places attention on the separateness of the individuals rather than the connections between them and misses the point of why individuals have and want children and “*the sorts of relationships people strive to create in families*” (Murray, 1996 p 30). So for instance, the situation becomes one where I speak of my rights and your duties to me (what I can demand of you by right), rather than on my dependence on you for most of my needs and the sacrifices you make because of our relationship.

Although rights may adequately protect many of the important needs and interests owed to children (food, shelter, clean air and water, security, and medical attention), they do not capture other as important obligations such as attention, love, compassion, and care. In this latter sense rights are inadequate for fully understanding the moral status of children and what they are owed (in the way of obligations) if they are to flourish.

A more encompassing account of children’s rights

James Griffin assumes that children have legal rights, but questions whether they have human or moral rights. In his account of human rights he argues that there is something special about human life. It is the fact that we are able to reflect on our lives and pursue goals that mirror that reflection - “*a characteristically human existence*” - that sets us apart from animals (Griffin, 2002 p 20). Griffin claims that human rights protect our human standing, our personhood. Personhood argues Griffin, is about agency, and being an agent is primarily about being autonomous.

He states that infants ought not to be seen as rights-holders because they are not agents; although children become capable of agency. He claims that if we extend rights to infants we adulterate the normative importance of rights. "*We should see children as acquiring rights in stages – the stages in which they acquire agency*" (*Ibid*). Thus he claims that whilst infants do not possess human or moral rights, children ought to be seen as acquiring those rights gradually as their capacities develop towards agency.

Samantha Brennan suggests that rather than focusing on either the choice theory of rights or the interest theory of rights, a more promising account (not unlike Griffin's) is a "*gradualist conception of rights which includes protections for interests and choices*" (Brennan, 2002 p 67). She rejects the claim that one must choose between either theory of rights. "*As children acquire the ability to choose, their rights will change from protecting interests primarily to protecting primarily choices*" (*Ibid.*, p 66). In other words, the interest theory of rights serves children when they are young (and unable to make choices that reflect their preferences), but as they mature the choice theory of rights best protects them (as they come to make informed choices). She claims that rights protect choices and interests, and in this way, neither account seen on its own in isolation from the other is correct. Brennan's account recognises that the rights of children and adults differ significantly because their interests are relevantly different. Children's rights predominantly protect their interests, whereas the rights of adults serve primarily to protect choices. Brennan also claims that children are persons (or at least potential persons) and as such they are entitled to the same moral consideration as adults (the equal consideration thesis). This means that "*children are to be taken seriously as moral agents, and that their moral claims are not to be discounted merely because they are children*" (Brennan & Noggle, 1997 p 2).

Conclusion

In this chapter I began by focusing on the concepts of moral status and moral obligation, and then looked at two differing accounts of what grounds moral status and consequently, moral obligations to children. Singer claims that the boundary of moral consideration ought to be drawn around all sentient beings. Under this account we have obligations to children because they are sentient beings that have an interest in avoiding pain and suffering. Under the rights account, children have moral status because they possess fundamentally important interests or can make authentic choices. As a result of these interests being recognised, they have certain rights which require the fulfilment of a number of moral obligations.

I claimed the sentience view does not go far enough in providing an account of why we have the obligations to children that we do. Whilst it is valuable in making a distinction between those beings who can experience pleasure and pain and those who cannot, and reminds us of the significance of the interest all sentient beings have in minimal pain and suffering, it is limited in clarifying the scope of our obligations to children. The unpalatable implication that we have no greater obligations to very young children than we do to many non-human sentient beings does little for our understanding of children's moral status (and hence, their lives) and how we should treat them.

Children are not simply immature adults who need to grow up (although growing up is part of what children must do). While it is fair to say that the language of rights has many valuable insights, especially in respecting the choices of autonomous individuals, or protecting the fundamental interests individuals have, rights theory is an inadequate way of understanding children's lives in terms of the obligations owed to them. So much of what children require to flourish cannot be captured by an appeal to rights. It

makes no sense to claim that children (or their representatives) can demand or waive their right to be loved, hugged or spoken to with compassion rather than anger. The obligation to provide these is inexpressible through rights' rhetoric.

I have argued that neither of these accounts despite their valuable insights goes far enough, nor do they do justice to the significance of children's moral status and hence their lives. In the next chapter I will suggest a different way of looking at children's moral status and the significance such a view has for why we have obligations to them.

Chapter 2: Children's unique moral status

Introduction

I began with the intuition that children are special members of the moral community who possess unique moral status which in turn obliges others to act in certain ways towards them. In the previous chapter I examined what some philosophers are committed to saying about the basis of those obligations to children. The language of rights and the account of sentience offer valuable insights into why we have some of the obligations towards children that we do, however I argued that neither account fully captures enough of them (the obligations). This suggests that we might do better to look for a different way to ground them.

In this chapter I outline what I believe is a plausible and compelling way of looking at why children possess unique moral status and why we have the demanding obligations to them that we do. My account offers a different way of thinking about children that both recognises their uniqueness within society and at the same time their similarities with others. It is precisely because they are understood in this way that we have the obligations to them that we do. We do not have the same obligations to, or hopes for, any other group in society in quite the same way.

An account of why children's moral status is unique:

(i) Children have fundamental needs that are crucial for their well being.

Children have a number of important fundamental needs (and/or interests) necessary for their survival and well being. These include adequate nutrition, clean water and air, shelter and warmth, security, clothing, the promotion of their happiness, and freedom from pain and suffering. As children cannot provide these things for themselves they must depend on others to satisfy them. The provision of these needs is extremely important if children are to develop in the ways they ought and they impose on others a number of positive obligations.

It is important to note however that these fundamental needs are also the same ones that all human individuals and many of the other animals have. Furthermore, like children, many adult human beings (those who are dependant on the care of others) and non-human animals (the very young and domesticated) cannot provide these things for themselves. All human beings and non-human animals require adequate nutrition, clean air and water, security and freedom from pain, which are necessary for their survival and well being. And although Singer claims in his account of sentience that all sentient beings have moral status and thus are worthy of moral consideration, he focuses more on the obligation to refrain from making them suffer, than any positive obligation to provide something to them⁶.

I have suggested that whilst children have many fundamental needs and interests, they are similar if not identical to the needs and interests of all other human beings and many non-human animals. There is nothing particularly special about children's needs in this respect; they are the same as all other individuals and many other animals. The fact that children have many fundamental needs and interests is not sufficient to justify the claim

⁶ One of the problems with Singer's account is that he cannot explain why we, as moral agents, shouldn't provide wild animals with medical attention when they are clearly in pain as a consequence of fighting, or why we aren't under a duty to ensure they have adequate food and water in times of drought and famine.

that children possess unique moral status. Keeping children's interests and needs in mind, we must look further.

(ii) Children are vulnerable

“The duty to protect the vulnerable is a duty to prevent harm from occurring; it is equally compelling whether it requires positive action or refraining from action. Failing to take positive action to prevent harm from befalling someone else who is particularly vulnerable to your actions and choices is morally akin to a bodyguard sleeping on the job” (Goodin, 1985 p 110-111).

Vulnerability is the single feature highlighted by the interest theory of rights which I examined in the previous chapter. The duty to protect the vulnerable is the kind of compelling duty to which we are inclined to say a right corresponds.

Of all groups in society, infants and young children are some of the most vulnerable because of their powerlessness and the fact that they are wholly dependant on the adults around them for everything they need for their well being and survival (others include the mentally disabled and the very elderly). As a consequence of this they are particularly susceptible to the decisions and actions adults make on their behalf. Whilst many adults make good decisions for their children and provide the best that they are able, children occupy a precarious position, for when the adults in a child's life fail to provide what children need for their well being, they are some of the first ones to suffer adversely.

Children's vulnerability can be evidenced in a number of significant ways. Young children are particularly susceptible to adverse outcomes if they are exposed to toxins in the environment⁷. Their immune systems are not fully developed, and whilst children are unable to metabolise certain toxicants, more commonly they have less ability to detoxify substances such as organophosphate pesticides which leaves them more

⁷ Particularly neurotoxic pesticides.

vulnerable to harms (Landrigan et al., 1999). In the prenatal period and the months and early years after birth, many of the body's organ systems undergo extensive growth and development which highlights the importance of protecting children from exposure to environmental toxins.

Children's physical vulnerability to infectious disease underlies the importance not only of immunisation, but the environment in which children live. One only needs to walk around the gravestones in an old cemetery to see how many children died as a consequence of contracting illnesses like scarlet fever, measles, pertussus (whooping cough), poliomyelitis, rubella, tuberculosis and diphtheria in our recent history. Many families lost several children to these diseases. Although children in New Zealand, and in many other developed countries do not die from most of these diseases today, a significant number of New Zealand children still contract measles (which can lead to permanent neurological damage), and pertussus (which can cause convulsions and death). Every year in New Zealand, children die from these preventable diseases. Children are extremely vulnerable to infectious diseases when they are young, not immunised and living in impoverished families and communities.

Children are also vulnerable to sexual abuse. A review of the long-term effects of child sexual abuse found a number of re-occurring themes that were sufficiently evident to make a number of significant conclusions (Beitchman et al., 1992). Adults who were sexually abused as children suffered from depression, were often re-victimised, showed evidence of suicidal ideas and behaviour and anxiety and fear. The severity of the harms experienced by abuse victims corresponded to the age at which abuse started, the duration of abuse, whether force or the threat of force was used and who abused the

child (*Ibid.*, p 115) (abuse involving a father or stepfather is associated with greater long-term harm).

There is also a growing body of literature that has studied children's vulnerability to domestic violence (Wolfe, Crooks, Lee, McIntyre-Smith, & Jaffe, 2003), (Osofsky, 2003), pornography, and the internet (Mitchell, Finkelhor, & Wolak, 2003), (Ybarra & Mitchell, 2005). It is clear that children are particularly vulnerable in relation to these situations and that their involvement in them can lead to adverse outcomes both in child and adulthood (McCloskey, Figueredo, & Koss, 1995), (McCloskey & Becker, 2002).

However, many of these vulnerabilities are not unique to children. The elderly, the incompetent and those in need of specialist care (individuals in hospitals for instance), are also extremely vulnerable to many of these situations, and the actions of others. For instance the elderly, like children, are especially vulnerable to infectious diseases; the elderly and the physically disabled, like children, are vulnerable to domestic violence; the mentally disabled, like children, are vulnerable to sexual abuse. Is children's vulnerability then, the same as many other groups within society? I do not believe it is.

Children share a special kind of vulnerability that is unique to them as a group. Their vulnerability is characterised by several distinct features which need to be viewed together: they are physically weak in terms of their strength and size (so they are susceptible to harm from their own actions and those of others); physically, at least when they are young, their bodies are still developing (hence they are vulnerable to injuries, exposure to chemicals, infectious diseases and poor nutrition); they are limited by their developing cognitive abilities (so that they often do not know what will benefit or harm them, or the consequences of their actions and behaviour); their voices are

generally not taken seriously, if at all (so that their desires and wishes remain unheard); and they are dependent on others for all their needs.

As I have noted previously, although children are vulnerable to the choices and actions of their parents and caregivers in determining how primary goods are distributed, they are also extremely vulnerable to the provision (or not) of psychological goods. We know that children need to feel secure, loved, made to feel special, receive attention and praise from significant adults in their lives and experience good role models. If children do not receive these important psychological goods their well-being will suffer.

Children who grow up in impoverished social environments face a bleak and damaging childhood.

Children's vulnerability is evidenced both in the present and in the future. What happens to children now has significant and considerable long term consequences not just for them, but for all members of society. I will reflect on the relevance of this in the discussion in (iv) of this chapter.

(iii) Children belong to us. They are 'ours'

Children are part of the human community and so are 'ours' in the sense that they are the same as us (human beings) rather than 'ours' in the sense of being 'our property' (a claim I will not examine)⁸ Children have no choice in whether they are born or not - a fact they will occasionally remind you of in adolescence! Their arrival in the world is solely the result, and therefore, the responsibility of others. Despite the fact that many children are born to individuals and couples who did not intend them or even want them, there are obligations owed to children simply because they now exist and are part

⁸ Jan Narveson claims that parents have property rights over their children; "*in view of human's enormous potential for third-party effects*" (Narveson, 1988 p 273), although these rights are restricted in "*what parents may do in light of this potential*" (*Ibid*).

of the human community. It is important to regard, not just biological parenthood as morally significant but the decision to take on parenthood for the duration of the child's life⁹. This includes parents who adopt, foster, or care for children whom they did not give birth to. In other words, the decision to 'become a parent' in the social sense, marks an important distinction in seeing parents as those who owe extensive obligations to children because they are 'ours'. This distinction marks a difference between a woman who bears a child and then gives it up for adoption and the woman who takes on the role of parent.

What is important about children being 'ours' are the relationships children have with their parent(s) or guardians (and to a lesser extent when they are very young, their relationships with their siblings and peers), and the value families bring to both its members and society as a whole. "*Families provide the setting for nurturing relationships characterised at their best by love, loyalty, and a healthy measure of forgiveness*" (Murray, 1996 p 23). As children mature and develop, the relationships they have with their peers become increasingly important and central in their lives. But what is significant about the relationship between children and parents?

Although individuals and couples have children for a variety of different reasons, generally it is true to say that parents want their children to develop into confident, happy and decent individuals who eventually are able to conduct their lives themselves. Thus a large part of one's relationship with children is involved in nurturing and developing those capacities and abilities that promote autonomy, self-esteem and confidence (I discuss the important principle of autonomy and its importance in relation

⁹ Generally the demands on parents diminish gradually as the child develops and matures into an autonomous adult.

to children in the next chapter). *“Well functioning families are the locus for the development of emotionally and physically healthy children” (Ibid).*

The relationship between parents and children is complex and intimate. Complex because the relationship undergoes tremendous changes as the child progresses from the stage of absolute dependency to a relationship more or less between equals. Intimate because parents and children know so much about each other within the relative privacy of the family. Children learn about their place in the wider context of the family; who they are related to and their familial history. In this way children see themselves connected to others in the wider context of the family and social relationships around them.

(iv) Children are the future

Although many individuals make the choice not to have children¹⁰, having and raising children is a part of what it is to live a human life. We do not think it unusual when people express a desire to have children of their own and raise them in a family¹¹. In fact whilst someone may question a couple’s decision not to have children, very few question why couples decide to have them at all; having and raising children is what adults do. It is a natural part of living a human life. Raising children to become competent, self confident, decent autonomous individuals, able to transverse the unpredictable journey of life, is the goal for most parents.

The relationships we have with our parents and siblings, especially when we are children, provide us with an important framework through which we initiate and develop relationships with others outside the family. These relationships form a

¹⁰ Sometimes one has no choice about having them, either through rape, ignorance, coercion, or lack of reliable contraception.

¹¹ I do not intend to discuss the nature of what ‘family’ means suffice to say it generally concerns adults and children involved in caring, loving, long-term relationships. Thus this very broad conception includes many kinds of relationships between adults and children.

valuable base on which we are able to successfully function in the world¹². As Murray so eloquently puts it, “*indeed, it could be said that the main point in having a child is to initiate the relationships that will develop between that child, its siblings, and the adults in its life*” (Murray, 1996 p 18). Hence children are the future in waiting.

Children are the reason we desire to protect the environment, prevent the destruction of the rainforests, limit the pollution we release into the air (and waterways), and control the proliferation of weapons of destruction. We care about these things not only for our own sake but the sake of our own children and their children. In other words, we care about how we act because we care about how our actions will impinge on the lives of children who will follow after us. We care about them because their lives are important to us. Not only their life right now, but their future autonomous lives as well.

As Narveson notes, “*The fact is that the children of today, being the adults of tomorrow, are also the producers of tomorrow and the supporters of the aged, and the utilisers of our wisdom, the bearers of the burdens of our errors and so on. In short they are the human world of tomorrow, and thus the repositories of much that we hold valuable*” (Narveson, 1988 p 271).

Children are the future in a very real sense: as they develop and mature into confident, competent individuals they step into the shoes of adulthood, become moral agents and leave behind the dependency and vulnerability of childhood. Children are our future; they are the individuals who will follow in our footsteps, look after us when we are frail, and continue our dreams and goals. Within a liberal society this transition is crucial. Children become citizens who are able to vote; they contribute to our moral

¹² Of course, I do not, and cannot ignore the reality that many families are troubled and dysfunctional, beset by jealousy, rivalry and bitterness. Families, especially for women and children, can be one of the most dangerous places for them to reside. However, I do not want to lose sight of the many beneficial and worthy functions families fulfil.

advancement and take on the responsibilities of citizenship. Children are an asset to society that we cannot do without and so we have a strong and crucial interest in how they are treated and the sorts of individuals they become.

“We all – parents and non-parents alike – have a stake in seeing these children raised well. We all share an interest in the optimal raising of our future citizens, neighbours, colleagues and friends” (Mills, 2001 p 17).

Finally, in chapter one I discussed Singer’s account of sentience in understanding children’s moral status. Under his account children miss out on being recognised as special in relation to many non-human animals because they lack important cognitive capacities that would give them greater consideration. However the fact that children will come to possess these important cognitive capacities (in the future) gives strong reason to think we ought to recognise their potential now, for we know with reasonable certainty that almost all children will develop into individuals who possess such capacities. Thus we must recognise that what we do for and to children now will have significant impact for their future lives.

Children’s unique moral status

When we reflect back, we see that this fourth feature of children – that they are the future – shows they possess the other three features in ways that differ importantly and relevantly from those other groups with whom they may share one or more of them. In the following discussion I will focus on what it is about children in respect to these four features that justifies the claim children have unique moral status.

I began by focusing on children’s fundamental needs, and noted that all adults and many non-human animals also possess the same needs and interests of children. Whilst one could argue that a failure to fulfil children’s needs and interests will have extremely

serious consequences for their lives, it is true to say that anyone deprived of them will suffer adversely; quite simply without adequate food, water, clean air, and a level of security and protection, all individuals and animals will suffer and die. However the subsequent healthy physical and psychological development that **only** children go through requires that we, as moral agents, have further obligations to children in respect of their fundamental needs. These include the obligation to ensure a minimal level of education, special sorts of medical attention (when required), love, attention and compassion. It also obliges us as parents, at least, to ensure that children are given opportunities to fulfil their potential, make friends, and develop self confidence.

Whilst any human being denied these things may suffer, children denied them will suffer adversely for the rest of their lives. They have fundamental needs that are crucial to their well being; not only in the short term, but for the whole future course of their lives.

Although I discussed earlier the notion of children's vulnerability, I believe that children's vulnerability and fundamental needs are unique in a very significant way with regard to their future. The decisions and actions that involve children's lives now will have important and far reaching implications for their (and our) future. For instance, the child who is denied an education and so matures into an adult who cannot read or write is vulnerable in a very relevant way in a society that assumes competency in these areas. He cannot participate fully in a society in which these abilities are required for almost every aspect of one's day. Being unable to read or write impacts severely and adversely on one's ability to make informed choices such as reading a legal contract, communicating with individuals in the written form and even basic but important actions such as reading instructions on medicine bottles.

Children's psychological needs also set them apart from all other groups in society and indeed non-human animals. Children require affection, love, compassion, empathy, acceptance, hugs, warmth, kindness, consideration, and understanding. Children need to know they are loved and accepted for whom they are, and that the adults in their lives will protect them and stand up for them because they care for them, not because children have earned such protection or deserve them. Whilst it is true that we all desire love and kindness in our lives, a child's need for these things is fundamental to their well being and flourishing in a way that is relevantly different to an adult's need for them. Adults may lack these important psychological goods (in their lives) because they treat others badly or fail to recognise how their decisions and behaviours result in others distancing themselves from them, but children cannot be held responsible for these important psychological goods being denied to them. Hence they are vulnerable to the provision of them in a way that adults are not.

Children's vulnerability is more significant than that of the vulnerable elderly individual because decisions made for children now will often have long term consequences not only for the individual they will become, but for all society, whereas decisions made for the elderly will not have such far reaching consequences. In a rather blunt way this can be summed up by stating that children are at the beginning of their lives whereas the vulnerable elderly are nearing the end of theirs. This does not mean, of course, that an elderly individual's vulnerability is insignificant, nor does it imply that we can treat them with disregard. What it does mean is that the vulnerability of children differs in important and relevantly different ways from that of the elderly individual.

I have proposed that there is something unique about children's moral status. They are special in that they have certain needs and interests that set them apart from adults (although they have many identical needs and interests in common too); yet they will leave behind this stage of development and become adults in time. These features give reason to claim that children possess unique moral status. This is because no other group in society has needs and interests in quite the same way. The elderly and the incompetent are vulnerable when decisions are made about them when they are unable to make decisions for themselves and often they have fundamental needs which must be provided for (sometimes indefinitely). They are also ours in the sense that we have caring and intimate relationships with them that are important.

Even domesticated pets such as the family dog and cat are vulnerable and have certain needs that must be fulfilled. They could also be viewed as being 'ours' in the sense that we have agreed (either explicitly or implicitly) to take on the role of carer to them. However whilst it is true that they, and other groups in society have certain fundamental needs and interests and are ours, children are the only group whose vulnerabilities are unique, who are our future and the future.

In the discussion on children belonging to us (iii), I claimed that the relationships children have with their parents are important and central to their lives. I do not believe the significance of parents to children's development can be overstated. How we, as adults, treat our parents, often has a great impact on their happiness, but their happiness is not dependent on how we treat them in the wholesale way that the whole future happiness of our children depends on the way we treat them when they are young.

Conclusion

Children occupy a special place in the moral community for whilst they are dependent on adults for all their needs when they are young they will develop and mature into moral agents capable of determining their own lives. Eventually they leave the stage of childhood behind. My account claims that children possess unique moral status as a result of four features about them; they have fundamental needs that are crucial for their survival and well being, they are vulnerable, they belong to us (they are 'ours') and they are the future. Whilst there are many individuals in society who are not children, yet are characterised by several of these features; and many non-human animals that also possess some of these features, only children possess all four and as such have unique moral status.

My account of why we have the demanding obligations to children that we do, offers a different way of thinking about children that both recognises their uniqueness within society and their similarities with others in the community. It is precisely because they are children that we have the obligations to them that we do. We do not have the same obligations to any other group in society in quite the same way and this has significant implications for what we owe children.

Whilst it is true that some children, due to their physical and psychological disabilities, may never leave dependency behind we still have obvious obligations to them because they are still vulnerable, require the provision of certain fundamental needs and are ours. However these children are the exception. It is the fact that children are distinguished by these four features that we have the obligations to them that we do. Quite simply, children grow up and (hopefully) become the autonomous, decent moral agents who may live next door to us.

Chapter 3: The parental role: obligations to children and autonomy

“Society does not reward those who choose to raise and educate children as it rewards those who choose more prestigious careers in medicine, management and law. It is not even clear whether we consider child-rearing a career or mere unskilled labour” (Shields, 1998 p 370).

Introduction

Whilst society may not reward parents it certainly recognises the importance of raising children well and this is especially notable when some children wreak havoc in our communities. Newspapers and the media regularly report the misdemeanours of children who break the law, often passing implicit moral judgment on the parenting capabilities (or the supposed lack thereof) of the parents. For instance, the employment or marital status of the child’s parent may be noted with the insinuation that it was because the parents were unemployed or ‘going it alone’ (in the case of solo mothers in particular) that contributed to the child getting into trouble. We may condemn those parents who raise delinquent and antisocial children but we are hardly forthcoming in our praise for those parents who raise moral, decent, caring adults. We simply expect that parents will get on with the job of good parenting once they have children and that those children will become healthy, productive and decent members of society. Parenthood, it seems is a role crucial to the well being of society and yet one that society hardly bothers to consider (until things go wrong).

We recognise the importance of children being raised in caring, loving families and assume that parents have the skills, ability and support to successfully undertake such a commitment, whilst at the same time propagating the myth that parenting comes naturally to those who undertake it. So while we may acknowledge the valuable role that parents play in the development and continuity of our society by raising decent children, we give little in the way of instruction or support to individuals and couples when they become parents. Moreover, parenthood is often idealised with unrealistic expectations of what is involved.

In the following discussion I will focus on the role of parenthood because it seems clear that an examination of the role is an obvious place to start when looking at who might have obligations to children, and something of what those important obligations may entail.

I begin by examining the claim that parental obligations are generated as a result of their having created children. I suggest that creating children is not necessary or sufficient for understanding those obligations. I then consider the claim that central to the role of being a parent is enabling one's children to become autonomous individuals, and something of what this obligation (to facilitate autonomy) entails.

Parents as responsible creators

“The fact itself, of causing the existence of a human being, is one of the most responsible actions in the range of human life. To undertake this responsibility – to bestow a life which may be either a curse or a blessing – unless the being on whom it is to be bestowed will have at least the ordinary chances of a desirable existence, is a crime against that being” (Mill, 1974 p 179).

Mill is surely right. Bringing into existence the life of another human being is an action that has profound, ongoing implications not only for the child herself and other family members but for all members of society.

However I want to suggest that whilst creating human life is one of a number of responsibility-incurring actions we could undertake, the role of nurturing and caring for that human life is a more responsible action. Being a good parent to one's child is more responsible than creating that human life. It's easy to create life¹³, far harder to ensure the life thus created is a life worth living. I believe Mill would have agreed with this distinction as he claims that *“if the relation between two contracting parties has been followed by consequences to others; if it has placed third parties in any peculiar position, or, as in the case of marriage, has even called third parties into existence, obligations arise on the part of both the contracting parties towards those third persons, the fulfilment of which, or at all events the mode of fulfilment, must be greatly affected by the continuance or disruption of the relation between the original parties to the contract”* (Mill, 1974 p 174).

Mill's position is clear: if two people create a child, certain obligations transpire to which they are accountable because they have 'called' the child into existence. Of course Mill assumed that children will be brought into being through the institution of marriage. Today many children are brought into being outside the context of marriage, or even a stable relationship between adults. Does Mill imply that couples who are not married or who have not entered into any contract together have fewer obligations to their children than do couples who are legally married? I don't believe he does. The spirit within which Mill writes is clear; parents have obligations to their own children because they created them and as such they are responsible for them and accountable to society.

¹³ Of course I recognise that creating life is not easy for many individuals who struggle with the issue of infertility. My point is that the physical act of creating life is itself not difficult for those who are fertile and have the opportunity to do so.

For Mill then, the obligations that are owed to children are to be fulfilled primarily by parents because they were responsible for bringing them into the world. What though of the child who is born as the result of rape or incest? Clearly in the case of a child conceived as a consequence of either circumstance, no-one wants to claim that the woman (or girl) was responsible for the creation of this child, yet we do feel that certain important obligations must be fulfilled in relation to the child. If the woman did decide to undertake the responsibilities of parenthood, then she is obliged to undertake them for a significant period of time. Even where a woman decides not to take on such responsibilities, she still has certain obligations to that child; namely to ensure the child is given the opportunity to be cared for by someone else who will love and cherish him or her. This is because “*a child must be brought up by somebody who cares for and loves her*” (Archard, 2003b p 49). Furthermore I would also suggest that the woman (indeed, any parent) has an obligation to ensure that the child has access to her genetic history should she want or need it later. In the case of individuals who donate germinal material that results in a birth, the subsequent child ought to be able to access their genetic history¹⁴ because such information may have important implications for the child’s future health. This does not seem to be inconsistent with Mill’s understanding of the obligations owed to children.

What about the couple who had no intention of being parents, who never gave much thought to the fact that their sexual activity might lead to the creation of a child, and now, having become pregnant do not want to be parents? One obvious option is to

¹⁴ In NZ in November 2004, the Human Assisted Reproductive Technology (HART) Register was passed. It now means that anyone donating germinal material (eggs, sperm or embryos) after the 22nd August, 2005, which results in birth, will automatically be named on the register. For individuals who donated germinal material prior to this date, the provision of information about themselves is voluntary. In the UK, donor offspring who were conceived using eggs, sperm or embryos from people who registered as donors after 1st April, 2005, will be able to consult the Human Fertilization and Embryology Authority (HFEA) register and find out who the donor was once they reach eighteen years of age. Such legislation recognises (at least in a limited sense), the importance of knowing one’s genetic history, if one so desires.

consider adopting the child out or aborting the pregnancy. But what if these alternatives are untenable for them (for religious or cultural reasons)? What are their obligations to the developing child?

There are risks associated with engaging in sexual intercourse: one may contract a sexually transmitted disease, discover infertility problems, or become pregnant. A part of involving oneself as an autonomous individual in a sexual relationship - regardless of whether it is a long term commitment or a solitary fling, is to recognise that significant consequences may follow. Where a couple engages in a sexual encounter, and where that act leads to a pregnancy, both individuals are responsible for that life regardless of the fact that they did not intend it and may not want it. Part of living an autonomous life is to accept the consequences and take responsibility for one's actions however harsh and demanding they may be. They may decide to have the child adopted out, or hand over the care of the child to someone else, but once they undertake to raise the child, they have a number of demanding obligations to that child which they are morally obliged to fulfil. In this sense their obligations are no less demanding than the couple who planned their child.

Whilst Mill is concerned with the fact that two individuals created the child (and therefore have responsibilities towards him or her), I claim that 'causing' the child is not necessary for understanding all our obligations to our own children. This is because parents who adopt children assume the same obligations as biological parents.

Parenthood is a role that most individuals take on willingly and voluntarily because it is a part of their important life plans. It is a choice that we make even if that choice may not be entirely free of the societal and familial pressures and expectations that individuals face in having children. Whilst the child may not have been intended (at that

particular time, or at all), deciding to become a parent signifies to society that a certain role has been accepted and undertaken. Some parents go as far to make that role and commitment explicit by baptizing their child into their particular religious faith. This signifies their commitment not only to the child, but to the members of their faith and the community of which they are a part; that he or she will be brought up in a certain way. Others participate in a ceremony where the child is formally named and welcomed into the community. What is significant here is that individuals and couples who undertake the role of parenthood recognise their obligations to their child. It is important then to look at what the role of being a parent entails in order to see more clearly what some of those obligations might be.

The role of parenthood

“Parenting is a job requiring nonreciprocal obligations, immense self-discipline and personal sacrifice” (Blustein, 1982 p 101).

Asked to describe what parenting may entail, parents would probably list some of the following features: demanding in terms of time devoted to the child, enhances family cohesion, changes intimate relationships between adults, new responsibilities, disrupts couples' shared leisure time, communication between adults changes, sacrifice, changing obligations to the child, excitement, frustration at times, lack of sleep (at least initially), stress, personal fulfilment, compromise, worry, a sense of achievement and changes in energy levels. There are no doubts many more. What is clear is that being a parent is a demanding role unlike any other social role we inhabit.

We cannot leave behind the obligations and responsibilities of parenting when we decide we have had enough. Neither can one be fired or made redundant from the position. Whereas the professional can leave behind the obligations associated with being a teacher or doctor after eight or nine hours work, parents simply cannot easily

leave behind the obligations that go with being Mum or Dad. The obligations one has to one's own children persist even when one is at work. So for instance, if the school calls me and reports that my child has broken her leg, I am obliged at the very least to ensure that she has received appropriate care. It would be a very peculiar parent who having established that the leg had been treated, refused to leave work to take the child home early¹⁵. What is important to stress is that parents continue to have obligations to their children regardless of their other social and professional roles. The role of being a parent cannot be relinquished during a busy day: the role itself is irrevocable.

Parenthood differs in other relevantly important ways from the other social roles we occupy. We need individuals to be parents in a way that we do not need lawyers or doctors or teachers. Without individuals wanting to become and in fact becoming good parents, society would be unable to continue far less flourish. Quite simply, if individual do not continue to raise children, the burden of maintaining society becomes extremely worrying. *“Every culture that is to survive must make provision for adding new members and giving them the skills needed to participate in the social and economic life of the community... [But] unless it succeeds in regenerating both the culture itself and its membership, a community will perish”* (Murray, 1996 p 8).

Related to this point is the importance of parents raising healthy, productive, decent children. Parents are the ones primarily responsible for the socialisation of children; that is, they impart to children the skills, knowledge and values that enable children to become decent, responsible human beings. *“Parents serve as children's first teachers and play a significant part in shaping children's attitudes, beliefs, values and behavioural styles”* (Bigner, 1989 p 35). The significance of this cannot be

¹⁵ Of course there may be circumstances where a parent simply cannot do more than establish that the child has received appropriate care – for instance if she was working overseas at the time of the accident, or if he was a doctor involved in surgery.

overestimated. Parental investment (or lack thereof) into their own children profoundly affects child outcomes notably in the areas of educational and occupational success, teen pregnancy and antisocial behaviour (Barber, 2000).

Children don't just learn from what they are told, parents are role models in as far as their own attitudes and beliefs about those around them reflect the value they place on others. Children, for better or worse, very quickly assimilate their parents' way of thinking. This is often highlighted when a child comments on a situation using language and gestures that a parent commonly employs in such situations. For instance, the child who repeats a stereotypical or offensive outburst at another driver's poor motoring skills, even though the child is clearly unable to fully understand what is meant.

Although we continue to learn as adults in the variety of social roles we occupy throughout our lives, the special kind of learning and influences we receive as children from our parents and caregivers can only be gained from growing up in a family environment.

Being a parent involves more than donating one's genes to subsequent offspring, carrying a child for nine months or giving birth, it means being an active participant in the nurturance and care of a child for a number of years because children cannot bring themselves up on their own. It entails obligations to ensure their child's health and happiness insofar as they can. *"It is not sufficient merely to produce children. The physical, emotional and developmental needs of infants, children and young adults – the group we now call adolescents – must be met"* (Ibid, p 8).

Archard makes the neat distinction between causal parents who are *"causally responsible for bringing a child into existence"* and custodial parents who are responsible, *"in significant part, for the upbringing of the child"* (Archard, 2003b p

70). Custodial parenthood involves instilling values, beliefs, traditions and customs, nurturing the developing child towards independence, teaching the child about consequences and providing him/her with goods that promote their well being and fosters self-worth. It is more than simply producing an individual who can look after him or herself. Parenthood entails (among other things) nurturing a child to make morally decent choices as opposed to selfish immoral ones, so that he grows up being a responsible and law abiding citizen. It is also a role that parents must gradually learn to relinquish once the child has gained enough maturity and independence to live their own life by their dictates. Parents must learn to 'let go'.

I do not believe that we can overestimate the importance of raising happy, healthy and responsible children. When children are raised to be decent human beings we all benefit. When children are not raised well, nobody benefits. "*We all share an interest in the optimal raising of our future citizens, neighbours, colleagues and friends*" (Mills, 2001 p 17).

The obligation to enable autonomy

I mentioned earlier that parents have an obligation to ensure their child's health and happiness. Of course one could object that we have these same obligations to our pets (at least to ensure its good health), and partners. What makes these obligations parental ones? I suggest that ensuring children's health and happiness is directed towards the end of the child's becoming an autonomous adult, which of course isn't true of one's pets or partners. In other words, I claim that parents are obliged to ensure their child's health and happiness which in turn requires the fulfilment of many other important duties so that children become the autonomous individuals they have an interest in becoming (who can successfully take charge of their own lives). So for instance, this

will entail ensuring not only that children's primary needs are met, but that they are provided with "*the kind of affectionate, appreciative and supportive upbringing that gives them a sense of their own value and a confidence in their abilities to fulfil their intentions*" (Blustein, 1982 p 128).

Central then to the role of being a parent is fulfilling those obligations that will cultivate and enable the child's developing autonomous capabilities. This will entail ensuring, as Mill observes, that children will come to exercise making their own choices, "*use observation to see, reasoning and judgment to foresee, activity to gather materials for decision, discrimination to decide, and when he has decided, firmness and self control to hold to his deliberate decision. He who chooses his plan for himself employs all his faculties*" (Mill, 1974 p 123). Parents are the primary nurturers in the development of their child's autonomous capacities and "*since children need autonomy, and since autonomy must be developed and fostered by particular psychological and educational circumstances from very early on in childhood, **parents have a duty to expose their children to such conditions***"¹⁶ (Blustein, 1982 p 131).

Mill was not the only commentator advocating the importance of education in the development of children's autonomous capabilities. Kant also argued that children, whilst not rational and autonomous like adults, nonetheless ought to be treated in a way that respects them becoming rational and autonomous individuals. Parents must provide not only food and care but they also have a duty to "*develop him both pragmatically, so that in the future he can look after himself and make his way in life, and morally, since otherwise the fault for having neglected him would fall on the parents*" (Gregor, 1996 p 65). Furthermore Kant argued that the education of children was crucial not only for children themselves, but for the improved future state of the humankind. For Kant, this

¹⁶ Bold emphasis is mine

duty to promote and facilitate children's autonomous capacities falls primarily on the parents.

We want children to grow into adults capable of making informed and considered choices about the kinds of lives they want to live because "*people need to be autonomous if they are to have good lives*" (Callan, 2002 p 118), and if individuals have good lives then society also flourishes. Thus we must ensure that they are given opportunities to learn to make informed decisions for themselves. Children as they mature and develop begin to take on more responsibility for the consequences of their decisions and actions and come to depend less on their parents for guidance and assurance in every aspect of their lives. They are further enabled in this enterprise when they see their parents making their own informed decisions and taking responsibility for their choices and actions. This reinforces to the child the importance of living one's own life from the inside, as well as appreciating the social ties that influence us all.

Letting go

I briefly want to return to the claim I made earlier, namely that in fulfilling the obligation to enable and facilitate children's autonomy, parents must learn to 'let go' when the child has reached the stage where they are capable of determining their own life. What does it mean to 'let go'? According to de Vaus, "*letting go involves the differentiation of two people*" (de Vaus, 1994 p 186). It is a process of being able to see not only oneself as a person in one's own right, but being able to see the other individual as a person in his or her own right. It is recognising a particular kind of relationship; "*one in which the other person is valued for his or her own sake and in which one is able to act independently of the other person's approval or expectations*" (*Ibid*).

Such a process surely begins early when, for instance, parents encourage their young children to settle with others (babysitters), successfully cope with going to (and staying at) school, staying over at friend's houses and being comfortable when left on their own for periods of time. Children must be allowed opportunities to experiment and try things out on their own so that they learn to take responsibility for their actions rather than relying completely on their parents for agreement. The process is not one-sided; *"it is also important to recognise that letting go is a task for both parents and children"* (*Ibid*, p xi). Adolescence is a time when parents must be willing to hand over control to their children and entails being supportive and accepting of them and the choices they make (Blustein, 1982 p 133).

The obligation to enable a child's developing autonomy necessarily involves being heavily involved in the child's life in terms of giving encouragement, direction, advice, chastisement, and in setting examples, but central to fulfilling this obligation is being able to step back gradually as autonomy matures and the child steps into the shoes of adulthood with all it requires of them.

Conclusion

I began this discussion by considering the role of parenthood. It is clear that while the role of parenthood is crucial to the health and wellbeing of children, it is also rather ambiguous, for there are no clear and absolute guidelines as to what constitutes competent parents (although we can make reasoned claims about what constitutes an incompetent parent). It is also true that being a parent differs from many of the other roles we will inhabit throughout our lives because we cannot easily discard it or refrain from carrying out its demands. We can say though, with reasonable certainty, that children thrive in families and communities where parents are confident in their

parenting abilities, where access to goods and services are affordable and available, and where family members are supportive and caring of one another.

I began by considering the claim that because parents are responsible for the creation of their children, they have demanding obligations towards them. This cannot be the whole story of why we have the obligations we do because children may be given up to others to raise. Simply being responsible for the child's creation is not sufficient to explain what parents are obliged to do for their children. It is the role of being a custodial parent that is significant in how we are to begin to understand what is owed to children. In deciding to become custodial parents, individuals assume obligations because they are responsible for their children: "*the duties that go with being a parent are the tasks and assignments for which a person becomes responsible as a result of having taken on this job*" (Blustein, 1982 p 101).

I suggest that at the heart of the parental role is the profoundly important and demanding obligation to nurture children to become autonomous individuals capable of living morally decent lives. This will entail the fulfilment of a number of duties such as ensuring the child's health and happiness (in as much as one reasonably can), providing good role models, promoting and encouraging the child's developing capabilities and 'letting go' as the child's independence and self determination develops and matures. How parents fulfil these obligations varies enormously even throughout similar societies and will depend on the resources and opportunities available, support of the communities in which they live, the experiences that are available to families and the cultural norms that are in place. What is clear about the role of parenthood is that the goal of raising healthy, productive, decent members of society is the desire of most parents. It is also clear that the important demands of this role cannot be overestimated.

My intention throughout this chapter was to consider why parents have the obligations to their children that they do, and something of what some those obligations may be. I recognise that my focusing almost exclusively on the duties that parents have towards their children has ignored much that is valuable about the parent-child relationship, namely the deeply affectionate and intimate bonds that exist between them. However whilst love, affection, care and devotion are crucial components of the parent-child relationship if children are to thrive and flourish, it is equally important to reflect deeply on what morality requires of us as parents in terms of our obligations to our children for at times it is easy to forget why children matter.

Chapter 4: Understanding our obligations to children: the role of all adults

“It takes a village to raise a child” (Ancient African proverb)

*“All New Zealanders should own and take responsibility for the care and protection of children and young people. The state has a responsibility to support communities and families in their role in caring and protecting children”*¹⁷

*“Each of us must come to care about everyone else's children. We must recognize that the welfare of our children is intimately linked to the welfare of all other people's children. After all, when one of our children needs life-saving surgery, someone else's child will perform it. If one of our children is harmed by violence, someone else's child will be responsible for the violent act. The good life for our own children can be secured only if a good life is also secured for all other people's children”*¹⁸

Introduction

I claimed earlier in my discussion that children are special members of the moral community as a result of their unique moral status (they have fundamental needs that are crucial for their wellbeing, they are vulnerable, they are the future and they are ours). They will also leave childhood behind and become adults in time. Seen in combination, these special features support the claim that children qua children are the recipients of a number of obligations owed to them by others.

In the previous chapter I critically examined the role of parenthood in illuminating why we have obligations to our own children. I claimed that we have extensive obligations

¹⁷ <http://www.msd.govt.nz/publications/care-protection-blueprint-2003/vision-guiding-principles.html>

¹⁸ Lilian G. Katz at <http://ceep.crc.uiuc.edu/pubs/katzsym/katz.pdf>

to our own children not only because we created them but also because we accept (either explicitly or implicitly) the demands of the parental role. From that discussion it was clear that the many obligations we have towards our own children arise not only because of their unique moral status but also from the nature of the parent/child relationship and the fact that parents are generally best situated to respond to their own children's needs.

Keeping in mind that all children are characterised by these special features that set them apart from all other individuals in society, does children's unique moral status require that we, as 'other adults', have demanding obligations to children generally? That is, do we have obligations to children who are not our own? In an ideal world all children would be raised in families and communities that could provide the loving and nurturing conditions children require to flourish. The reality as I have noted previously (in the introduction of section one), is that many children have impoverished and bleak lives. It is important therefore to consider what, if any, obligations we have towards children who are not our own because it is clear that many children have been failed, not only by their parents, but also by society. It is also clear that children are not to blame for the miserable lives they are often forced to endure.

A friend related the following story: On his way home early one evening, her partner drove down a busy suburban street where two very young children were playing. There were no adults in sight. The youngest child who looked to be around two years of age was riding his bike on the road whilst a slightly older child sat on the footpath. Noticing the children he continued driving home. Casually relating the situation to my friend later that evening he was surprised and defensive that she criticized him for not stopping. Surely, she remarked he should have at least stopped and found out where the

children lived ensuring that someone was aware of where they were; after all, they were in a potentially dangerous situation and could have been injured or killed. “*You had an obligation to them*” she said “*because there was a strong likelihood that they could have been hurt*”. He responded that he had no such obligation and that any duty to protect them from harm lay fairly and squarely with the children’s parents.

And of course he is right. Parents do have a duty to ensure their young children are safe from harm but regardless of that, the fact remained that two very young children were playing on a busy street with no adult in sight. How would my friend’s partner feel were he to hear later that another driver not seeing the child on his bike hit and killed him? Perhaps he would continue to admonish the parents for not knowing where their children were; perhaps he would feel guilty that he had seen them and done nothing to prevent a possible tragedy. He may reason that the children were not his. He didn’t allow them to play on the road exposing them to the myriad of dangers they faced; he was merely driving by minding his own business. He may further respond that the children belonged to someone else and to start knocking on doors to determine who they belonged to and why they were playing on a dangerous road, was to violate some fundamentally important aspect of familial privacy. If he was very honest, he might respond that whilst he noted the children playing on the side of the road, he didn’t really appreciate the significance of what he saw – after all, they were just children.

Whatever his response, the fact remains that both children were in a potentially dangerous situation and he had the ability to assess that danger and do something about it without significant cost to himself. The parents were responsible and accountable for the children’s exposure to such harm (in as much as we know about the situation.

Perhaps they were the responsibility of a negligent babysitter or had ‘escaped’ from a

child care centre), but so was my friend's partner in not coming to their aid. He had an obligation to the children that he failed to fulfill and so his inaction brings moral disapproval.

The obligation to protect others from serious harm if we can so do without sacrificing too much is one that is morally required and one that Peter Singer claims we are obliged to fulfill to everyone (Singer, 1993b p 229-232). It is a duty we are generally in agreement on even if the actual demands on us are rather less clear in practice. For instance, I might agree that I have an obligation to prevent a child being harmed if I can, but be unsure how far such an obligation extends: for instance, should I adopt the child I had a hand in rescuing from an abusive family environment, and how much money, time and expertise should I donate to organizations that seek to eliminate global childhood starvation and malnutrition? Despite this, it remains that we ought to help and do more than we currently do even if we are unsure how far such a duty extends. Lack of clarity in how far our obligations extend is not an excuse for doing nothing, even if it often functions as one. In fact Singer claims that were we to take the demands of this obligation seriously, we would see that "*our lives and our world would be fundamentally changed*" (Ibid., p 230).

In situations where the harm to children is likely and the cost to adults (in preventing the harm from occurring) minimal, it is not contentious or inappropriate to claim that adults have an obligation to protect children from such harm where they can – no matter who they belong to – and failure to do so makes one morally culpable.

We begin then with the claim that children stand within the moral community in a special position because of their unique moral status. In the previous chapter I claimed that their particular moral status and the role of being a parent combine together to

support the demanding obligations owed to children by their parents. But what about our obligations to children who are not our own? How far do those obligations extend and how demanding are they? I take it as a given that we have an obligation to protect children from serious harm (where we can), but do we have obligations towards children who are not our own even when it is clear children are not in any 'clear and present danger'?

In this discussion I will consider this question in light of morality's demands on us as moral agents. There are important parallels between arguments for obligations of the affluent to help those whose lives are dictated by wretchedness and deprivation, and arguments for obligations to children other than our own. I look at one such argument in this discussion; what the principle of impartiality requires of us in the context of our obligations to children who are not ours. I then focus on what some of the practical implications for us as moral agents may entail. I will not focus on our obligations to those children in distant places (those who are geographically isolated from us), although I agree with the many commentators who write on this issue that we have a duty to do far more than we currently do to help them (Unger, 1996), (Singer, 1993a), (Lafollette & May, 1996). My focus is on those children who live in our own communities.

Before I begin I want to briefly consider and dismiss a justification not to act that was alluded to earlier in response to the case of the children on the road. It was suggested that one may defend one's actions not to help the children because '*it's none of my business*'. Perhaps what lies behind such an assertion is the idea that what goes on in other families is outside the boundary of my concern or business: that is, we ought to

respect the family's privacy and not intervene in what is a family matter because the children are solely the responsibility of their parents.

Although we often hear individuals justifying their decision not to act in a particular situation by claiming '*it's none of my business*', in the context of this particular case, one's inaction raises an immediate question: why isn't the welfare of two young children my business when it is clear that they are in a potentially dangerous situation? Clearly they are unable to appreciate and assess the danger they are in because they are simply too young and they lack the requisite cognitive abilities. I however do not and as such the least I can do is to remove them from the danger they face because the risk to me is negligible and the benefits to the children significant. It is not in the interests of both children to remain in such a dangerous situation. Assuming that the parents were unaware of the dangers their children faced, I would hope that in a similar situation, my own children would be rescued.

From a purely self interested perspective, I have a vested (self) interest in the wellbeing of these children who will grow up and become citizens. As members of their generation, they will support me and mine in old age, continuing the amenities and services I will need when I am no longer able to contribute financially to the economy. In brief, the statement, '*it's none of my business*' at least in the context of this situation, fails to justify one's (in)action towards the children.

There is an important sense in which focusing on the rather abstract notions of obligations and responsibility with regard to children misses what is important about our relationships with them. When considering the case of the children on the road, my friend's partner clearly did not think he had any duty to help, but even if he did he may not clearly articulate the many reasons why he should. He may have quickly assessed

the situation and instinctively stopped to make sure the children were safe from danger, barely giving it another thought as he drove away. He may have felt it was simply the 'right thing to do' in the circumstances without being entirely clear why that was the case.

However sometimes our instinct does not direct us to do the morally correct action; we need to be reminded of why children matter and what obligations we have to them. I do not mean to trivialize or minimalise the many other important reasons one may give to benefit children (for example, we love or care about them, or we recognise in them what we lacked as a child and want to better their lives), rather my aim in this discussion is to clarify why we owe children (who are not our own) what we do.

Moral impartiality

According to James Rachels the notion of moral impartiality (the idea that “ *we may not draw circles around individuals and groups and declare that they are to be treated as “special” when moral decisions are made*”) is an important one that we ought to retain because “*it seems to express something deeply important*” (Rachels, 1997 p 214-15). It expresses our moral repugnance when individuals or groups are set apart from others and treated as “special” solely on the basis of their gender, religious or ethnic identity. It expresses why we find sexism and racism morally odious and allows us a “*persuasive means of combating those doctrines*” (*Ibid*). Although he claims that we are right to think that we have special obligations towards our own children, we are wrong to suppose that we have very few obligations to other children, even those who are geographically isolated from us.

Peter Singer holds a similar but more demanding view about what moral impartiality obliges us to do for others. He claims that as equality is a basic ethical principle, we

must consider the interests of all others equally when we are making ethical judgments (Singer, 1993b p 21-22). This is not to say that we must treat all others equally: it means that we cannot act partially when we are considering the interest of others (unless there are morally significant reasons to justify acting so). Thus like Rachels, Singer claims that impartiality is a cornerstone stone of morality and our obligations to others are far more extensive than our intuitions may imply.

At its heart, moral impartiality is underpinned by the notion of consistency. Consistency is a central tenet in ethics and requires us to apply similar assessments about similar actions unless we can show that the actions are relevantly different: at its heart morality is about the absence of inconsistencies. Furthermore it also upholds the view that each moral agent counts equally with all others. If as I have suggested, all children are characterised by certain features then it follows that their interests will be broadly similar even if the actual lives of children differ considerably: all children require the provision of certain fundamental needs (adequate nutrition, clean water and air, medical care when necessary, shelter, and security), all have an interest in being loved and cared for, all have an interest in being assisted to reach their potential (which means they can go on to live independent and autonomous lives), and generally most will become adults who will become citizens and may go on to have children of their own. As such it cannot be consistent to say that we have an obligation to provide children in Auckland with nutritious food and clean water but no obligation (to provide the same), all things being equal, to children in Dunedin.

Applying the notions of consistency (equal consideration of interests) and impartiality in our dealings with children requires us to consider not only the needs and interests of our own or those close to us, but children who are not our own. If children are to

flourish and become productive, successful, decent members of our society, then it would seem that impartiality requires us to consider their interests seriously and act accordingly.

However our profoundly deep intuition that we are morally permitted to prefer our own children (to others) is powerfully compelling. We love our children in ways that we do not love other people's children no matter how magnanimous we feel towards them, and the relationship we have with those we love and care about seems *prima facie*, to justify partiality. In fact to treat one's own child as merely one among many others is considered morally dubious. The parent who takes no special interest in her own child's life and who sees nothing particularly worthy of note in his or her abilities or achievements lacks the qualities we expect and assume a parent will have for her own child. Such a parent is deficient in morally significant ways.

Therefore it seems we have a problem: we want to hold on to the deeply intuitive notion of impartiality yet at the same time we also want to hold on to the idea that we can favour those personal relationships we have with our friends and family members (Rachels, 1997). In other words, we think we are morally justified in drawing circles around certain individuals and groups and declaring that they are to be treated as 'special'.

Rachels considers the reasons one may hold for thinking partiality is justified: in the context of day-to-day life parents can best provide the personal attention that children require (because they are physically there to do it); the loving relationships that parents and children have together are part of what it means to have "*a rich and satisfying human life*" (*Ibid*, p 223); our intuitive sense holds that concern for one's own is natural and innate, and finally parental duties are special duties that one has to one's own

children in virtue of being a parent. Rachels considers these reasons and concludes that although they generally offer strong reasons to justify partiality in the treatment of our own children we also “*have a substantial obligation to be concerned about the welfare of all children*” (*Ibid*, p 230). We can, Rachels concludes, retain both ideas. We can hold on to the idea of morality as impartiality whilst also keeping firm the idea of special parental obligations (*Ibid*, p 216).

This he claims, allows the following: parents can permissibly continue to provide the loving ‘day to day care’ of their children whilst giving them preferential treatment in the provision of life’s necessities (for instance, providing for their fundamental needs, listening to their stories and jokes, playing with them and attending to their worries and concerns). However, we ought to prefer “*to provide the necessities for needier children rather than luxuries for our own*” (*Ibid*, p 231). This is because all children require the fundamental necessities (such as food, shelter, clean air and water, and healthcare) to survive. As Rachels notes, “*...even in a fairly weak form, this view would require much greater concern for others than the view that is most common in our society*” (*Ibid*).

Practical implications of our obligations to children who are not ours

As Rachels rightly notes, parents are generally best placed to provide for their children’s needs (physical and emotional) and society recognises this by granting parents wide ranging (although not absolute) authority in how their children are raised. If, as Rachels claims, we have a substantial obligation to be actively concerned with regard to the lives of children generally, what might this mean for us as moral agents towards children who are not our own? What might this ‘greater concern for others’ entail? I suggest it requires, at least the following:

Obligation to be informed about governmental policy regarding children's lives

“One of the most important tasks of government is making provision for the healthy development of children, especially those in vulnerable circumstances” (Ministry of Social Development, Fergusson, Horwood, Ridder, & Grant, 2005 p viii).

As the state is entrusted with the authority to intervene in the lives of families and individuals and make decisions that will impact deeply on all of society's members then all citizens *qua* moral agents have a duty to be interested and informed about the various political parties represented in government at least in regard to its position on children. We ought to be concerned and interested in what policies the government will act on because not only do such policies impact on our lives and the lives of children in a myriad of different ways, but we are responsible for choosing who will represent us in government. We elect them and so must be accountable for the governance we get. We should ask questions such as; what will your party do to eliminate or ameliorate child poverty, what policies seek to improve the lives of poor children, how much emphasis do you place on primary and secondary school education, how much of your budget targets helping families better their circumstances and improving the flourishing and well being of all members of families, how will your party respond to the appalling child abuse statistics in this country, and what assistance will be given to promoting the health and well being of children?

Concerns about the ways in which government responds to the lives of children were captured in a letter to the editor of a national newspaper recently; *“With tax cuts being bandied about, this looks like the usual what's-in-it-for-me' election. But what about children? They have no say, although they are the future of the country. They should not be a mere afterthought in three-yearly political grab for power. I will vote for the*

*party or parties that show they really care for children and want to create the conditions for them to flourish and become good citizens in a fair society”*¹⁹.

A political party that fails to recognise the importance of children and their lives now, and their future well being is one we should be very wary of bringing into power and supporting with our vote.

Obligation to pay taxes

“We need to raise investment in children. The wellbeing of children is not only a moral obligation for society, but is also the key to future economic growth and a central element of strategies to reduce poverty” (Progressive Governance Summit. *Final Communiqué* July, 2003).

We also have a duty to pay the taxes we owe. A significant proportion of our taxes fund those organizations and agencies that provide services to children and young people, notably the provision of schools, educational facilities and health care. Even if we do not have children of our own, the taxes we pay today contribute to the well being of children who will one day grow into the adults who will support us in our old age. In 2000, the United States Libertarian Party claimed, “... we further support immediate reduction of tax support for schools, and removal of the burden of school taxes from those not responsible for the education of children”²⁰. Surely such a view is short sighted?

The individual who denies she ought to pay taxes that help support children who are not her own has lost sight of the fact that she was benefited tremendously by those adults generations before her who paid taxes and contributed to the society she now takes for granted. Many of them may not have had children of their own yet we have all

¹⁹ Geoff Barlow. The New Zealand Herald, Letters to the Editor. 1st October, 2005.

²⁰ National Platform of the Libertarian Party Jul 2, 2000, at http://www.issues2000.org/Celeb/Libertarian_Party_Education.htm

benefited from the decisions, actions and sacrifices taken by those generations ahead of us. We take for granted the benefits we have inherited like the protections of law and order, security, knowledge, traditions and utilities and social institutions like schools, libraries, hospitals, and universities. As these services, utilities and agencies cannot exist without financial input from taxation, and as we all benefit from their continued existence, we have an obligation to pay the taxes we owe. We have a debt of gratitude to those individuals who went before us, a debt I believe we have a duty to repay; in part by ensuring we pay the taxes we owe that contribute to the wellbeing of those who come after us.

But our duty to pay taxes is not solely or even primarily because we have a debt of gratitude to those who have gone before. Surely if we want to live in a society of educated citizens whose enterprises flourish and succeed we need an educated workforce (Partridge, 2005). If the burden of funding education falls only on those with children then we will see a disintegration of the education system as only the rich will be able to finance their children's education. Poor children will not be able to afford to go to school, and even those with middle incomes will undoubtedly find it difficult to assist their children on to tertiary education. In short we all lose out because the education level of our up and coming generation will degenerate. It is not difficult to see how such a vision (that one has no duty to pay taxes to support children who are not ones own) is deficient: those who cannot attend school or access health care because their parents or families cannot afford it fail to reach their full potential, thus denying society the diversity it requires to succeed and flourish.

Obligation to respect children's lives

Although we have made important strides in recognising the importance of children's lives and implementing strategies to improve them we are often dismissive and

intolerant of children generally. It is not uncommon to hear individuals criticize children and their behaviour. *'When I was young'* is often followed by a litany of how children these days have no respect for their elders or that they are too lazy, rude, unimaginative or self absorbed. The inference is often that children were somehow 'better' in the past.

Yet children are also viewed by many as requiring protection from all possible risk no matter how small or remote the harm actually is. A recent example bears this out. Recently the seating policies of Air New Zealand and Qantas were publicly aired in the media when a male passenger, seated next to an unaccompanied minor, was asked to move from his seat to another in the plane. It transpired company policy stated that males were not to sit next to children who were traveling on their own because of the possible risk of harm to the child. After the incident was publicized the response in the media was swift and revealing. Some men complained that such an action was discriminatory and offensive towards males, many of whom had children of their own. Many loudly applauded the airlines' policy suggesting that they were glad not to have to be seated next to 'squalling brats' and commiserated with the woman who would now have to bear such a burden. There were some who commented that children should be banned from flying altogether until they were old enough to sit quietly and behave, or that airlines should implement 'adults only' flights. Many women commented that they would rather not have to sit next to children who were traveling on their own; 'why not just seat all unaccompanied minors together and away from all adults?' was a typical response to the issue. One woman recognised that the risk of her child being harmed was slight, but still claimed it was a risk she wasn't prepared to take.

The debate exposed a powerful division in the way we perceive of children in our society. It would seem that children are at the same time both a burden to be endured and a very vulnerable group deserving of the utmost protection and security. If children are to thrive in our society and go on to become decent, productive human beings, we as a society need to exhibit tolerance and respect for the energy, unpredictability and liveliness that is childhood. At the very least we must recognise that we were once children and our lives were respected by adults.

Obligation to support families with children who have special needs

Children stand in a special place in the moral community, but they are not standing entirely alone. Generally all children are situated within families where there is at least one adult who loves and cares for the child. Within many families reside children who live with special needs that require additional support and care from both their families and the community in which they live. These children are particularly vulnerable and as such constitute a group to whom we have further obligations.

These are children who live with physical and psychological disabilities, but it also includes children who are born with diseases that will onset either in child or adulthood. What obligations do we have to these children? Many of their needs will be addressed by the welfare and legal system. The state has certain obligations to these children that they do not have towards children generally. For instance, many of these children will attend special schools (with additional support and services); others may require professional help in order to develop to their potential. This may include specialist guidance and support, specific equipment or medical therapies and treatment.

I claim we have an obligation to support these families in a variety of ways. Such an obligation may simply involve offering encouragement and empathy when the adults in

the family are experiencing difficult times with the demands on them from their children's needs. It may involve practical support when families need help arranging transport to hospital. In a fairly broad way, this kind of obligation can be understood as one of requiring support and empathy for families facing difficulties and particular challenges with their children.

Comment

One may respond that the actual demands on us as moral agents as far as our obligations toward children who are not our own are concerned are too vague and imprecise to be of any real relevance or practical use. Yes, we ought to protect all children from serious harm and yes, we ought to be more aware of the kinds of lives many children lead, but it is often difficult to know what one can actually do to help. It is the familiar cry; "*what can I do when I am only one individual and the problems are so huge?*" When one hears that many children in South Auckland have never celebrated their own birthday or traveled beyond the limited boundaries of their local community²¹ it is easy and understandable to wonder what one can do to help when the issues are often not solely about a lack of financial resources. How do I fulfill my obligations to children who are not obviously at risk of serious harm yet who may be seriously disadvantaged because their parents lack parenting skills or who are indifferent to the needs and interests of their children?

I recognise that the answers are not easy or straightforward. Neither are they solely confined to the almost crushing issues of poverty and despair that seem to overwhelm those people who think about the plight of children generally. Yet what I have argued is that this does not excuse us from thinking deeply about the interests and needs of children and resolving to keep them foremost in our minds. At times it will require us to

²¹ National Programme with Linda Clarke, 14th December, 2005

speak out on behalf of children and perhaps to intervene to assist them in a variety of different ways. It does not excuse us from fulfilling our various obligations to children because the problems are seemingly large and complicated. As moral agents we must confront the reality of children's lives, the important obligations we are required to fulfill and the ways in which we live our own lives – lives that in many instances are surrounded by children who are not our own.

Conclusion

“Families, although they constitute a distinctive sphere of human life do not and cannot exist in isolation. Just as children need families and many adults need children, so do families need supportive social institutions and communities. Without a web of support in the wider culture, individual families may collapse under the weight of external blows and the inevitable injuries that even the best of families inflict on themselves” (Murray, 1996 p 24).

Most of us see and hear children everyday. We pass them on their way to school; sit next to them on public transport, share planes, public amenities and suburbs with them. Some of us live with them. Sometimes we may see or hear about children in our own communities whose lives are impoverished and filled with abuse and neglect; often we are reminded of the miserable, bleak lives of children living in countries geographically isolated from us. In both cases we may wonder about what we can do; hardly ever do we reflect on what we ought to do.

The notion of moral impartiality has much to contribute in illuminating our obligations to children who are not our own. At its heart lies the idea of consistency. If we believe, as I suggest morality dictates, that we ought to apply similar assessments about relevantly similar actions, then we cannot ignore the lives of children who are not our own. However it does not simply imply that we ought to treat all children in the same way. Such a suggestion is clearly ridiculous. Parents have authority over their child that

allows them broad latitude in how they bring them up, and quite simply we cannot care for every needy child we come into contact with.

However consistency requires us to fulfill certain general obligations to all other children by being informed about our system of government, paying our taxes, and being respectful and considerate of children's lives (especially those with additional needs). I argue that as morally decent individuals, this is the least we ought to do in relation to children. I began this chapter with an African proverb; 'it takes a village to raise a child'. We are all villagers, and we all have demanding obligations to the children living within our village.

Chapter 5: Protecting children from serious harm: is licensing parents the answer?

Introduction

In previous chapters I have focused rather theoretically on the moral status of children. This has entailed thinking about children generally and what is owed to them because of certain qualities they possess. Unfortunately, as I have noted, many children live lives characterised by violence, abuse and neglect.

In this chapter I consider a practical situation that seeks to protect children from serious harm; that of licensing individuals before they become parents. If, as I have suggested we have an obligation to protect children from harm, and knowing that some parents harm their children then perhaps we ought to consider licensing individuals before they have children?

The idea of licensing individuals is not new. During the mid nineteenth century some European countries regulated the reproductive abilities of citizens. At that time John Stuart Mill claimed that those countries who “*forbid marriage unless the parties can show that they have the means of supporting a family, do not exceed the legitimate powers of the State*” (Mill, 1974 p 179). He argued that laws which restrict those individuals who can become parents are not objectionable violations of liberty.

More than twenty five years ago, Hugh LaFollette wrote a radical paper in which he claimed that “*the state should require all parents to be licensed*” (LaFollette, 1980 p 182). Not only did he claim that such an idea was theoretically desirable, he also claimed that a licensing program was practical and ought to be established. His claim was based on the premise that an activity which is potentially harmful to others and necessitates a certain competence to be safe ought to be subject to regulation. Since parenting is an activity that requires individuals to be competent and it can and sometimes does harm children, it follows that parents ought to be licensed. At the heart of LaFollette’s licensing proposal is the protection of children from serious harm.

I begin the discussion by briefly giving some background to the issue of licensing individuals and then I consider the notion of serious harm that LaFollette employs. LaFollette focuses exclusively on the serious harms that result from physical abuse, neglect and maltreatment, however I claim that moral consistency demands we broaden our awareness of what constitutes serious harm. I reflect on the serious harms children suffer from three different perspectives: growing up obese, living in a smoky environment and being raised in poverty. In all cases I suggest that the harms children suffer as a direct result of living in such circumstances are serious. Although one may claim that this strengthens LaFollette’s claim (that is, it provides further justification to license individuals before they become parents), I argue that the practical consequences of such a licensing program will result in **far** greater harm to potential parents, those who are already parents and to the children themselves.

Finally I suggest some alternatives to licensing. I conclude that a licensing program such as LaFollette’s is morally impermissible. However this is not to suggest that we ought not to seek ways to reduce and ameliorate the serious harms that are done to

children. As parents and adults we have an obligation to protect children from serious harm.

Background

Since Lafollette's paper there has been impassioned discussion over the licensing of parents. In 1994 Jack Westman wrote 'Licensing Parents: can we prevent child abuse and neglect?' He argues that the licensing of parents is "*eminently logical*" and would "*convey the message to all elements of society that child rearing is a vital social role. It would heighten public awareness that competent parenting is essential for the wellbeing and even survival of our society*" (Westman, 1994 preface xiii).

In 1996 the journal *Society* held a symposium on licensing parents. The contributing authors were polarized in (both) their support and rejection of the proposal to license parents.

Psychologist Katherine Covell and political scientist R. Brian Howe also advocate the licensing of individuals before they become parents. Their licensing procedure would impose three requirements on individuals:

- Individuals would have to show that they were responsible for their own lives before they were allowed to have children of their own.
- They would have to sign a contract agreeing not to abuse or neglect the child or allow anyone else to.
- They would have to attend a certified parenting course (Covell & Howe, 1998 p 34-35).

In 2000 David Lykken proposed that sociopathic young people were the disastrous products of incompetent parenting. Licensing parents, according to Lykken, would eliminate this “*cycle of human waste*”. Only those who were over “*21, married, self supporting and who had not been convicted of a violent crime*” would be licensed and any unlicensed individual who had a child would lose them to adoption (Lykken, 2000 p 595). “*The infant would be removed at birth and placed for permanent adoption. If either parent had participated previously in an unlicensed pregnancy, he or she would have to submit to a Norplant or similar long-acting contraceptive implant*” (*Ibid*).

More recently Peg Tittle edited a diverse collection of articles addressing the licensing of parenthood (Tittle, 2004). It is clear from the discussion that Lafollette’s proposal generated within the literature, that the licensing of parents is controversial and enduring. Controversial because commentators such as Lykken and others (McIntire, 2004) advocate a very punitive licensing program, and enduring because at the heart of Lafollette’s proposal to license individuals are crucial questions about how involved the state ought to be in the matter of raising children, and the importance of children’s lives and the value we attach to them. We cannot escape thinking about these questions in relation to licensing individuals.

Children’s lives and serious harm

It is important to revisit the position put forward by Lafollette in light of where children stand today because since Lafollette’s paper was published, the lives of the world’s children have changed considerably in many different ways. Nine years after Lafollette’s paper the UN Convention on the Rights of the Child (UNCRC) was enacted. Children are now recognised as having significant rights against others. For instance, children have the right to “*maintain on a regular contact, save in exceptional*

circumstances, personal relations and direct contact with both parents” (Article 10). Children also have a right to be protected “*from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse, while in the care of parent(s), legal guardian(s) or any other person who has the care of the child*” (Article 19). However acknowledging the rights of children does not exhaust our obligations and responsibilities to them as noted in chapter one.

In New Zealand we now have a Commissioner for Children (established under the Children, Young Persons and Their Families Act 1989) who “*speaks out on behalf of all children to ensure their rights are respected and upheld*”²². There are also a number of social changes that have occurred over recent years which are not outstanding on their own but when seen together point to a more child-centered view: the development and resourcing of public education programs to educate parents, legislation requiring the fencing of swimming and spa pools, and the more stringent regulations in place for individuals and businesses involved in the care of children (play groups, kindergartens, crèches, care facilities and pre schools). In New Zealand all schools now have risk management strategies in place when children are involved in activities that may put them at risk – camps, overnight trips, sports events and swimming activities.

It is also interesting to note what members of the public have to say about children. Two different comments, in a national newspaper recently, make the writer’s view quite clear. One asks, having witnessed a family sitting in a car next to her at traffic lights; “*How can people think it is acceptable to smoke in the car with small children when*

²² Children's Commissioner. (2004). *Advocacy*. Retrieved February, 2005, 2004, from http://www.occ.org.nz/childcomm/about_us/advocacy

*you are legally prevented from smoking in bars?”*²³ Another writer states; “A recent report said every year hunger kills 11 million children below the age of 5. And that there are 211 million child-labourers in the world, and 300,000 child soldiers. Every year, four million girls are bought and sold for marriage, prostitution and slavery, and two million girls face genital mutilation. The (NZ) Government is very agitated, it seems because the Japanese are killing 1000 whales. I do not care about these “magnificent creatures”. Does anyone care about children?”²⁴

At the time of writing members of parliament are debating the issue of physically disciplining children in relation to Section 59 of the NZ Crimes Act (the Act allows parents to discipline their children with reasonable force). Public debate suggests that society is deeply divided on the issue of disciplining children with reasonable force, although a majority appear to support repealing the Act. Central to the issue is a lack of transparency in what constitutes ‘reasonable force’. I suggest that such a debate has emerged primarily as a result of recognising and taking the interests of children seriously: especially their interest in not being physically harmed.

However, despite the numerous number of documents that recognise the primacy of children’s welfare, their right to be free from all forms of abuse and violence, and the more enlightened view about children’s lives, many agencies in New Zealand report subjectively that the level of violence being delivered on children is increasingly severe.

Recently New Zealand’s top family court judge, Peter Boshier stated that, “*we can no longer boast of being the best country in the world to bring up children*”²⁵. Domestic violence statistics show that about 6000 children, more than half under the age of five

²³ Sideswipe column, The New Zealand Herald, 8th March, 2006.

²⁴ Mike Edgar. The New Zealand Herald, Letters to the Editor. January, 2006

²⁵ http://subs.nzherald.co.nz/topic/story.cfm?c_id=178&ObjectID=10374676

years old, witnessed family violence during the Christmas and summer period Dec 2005 – January, 2006. Boshier continues, “*I believe we are observing signs of a very serious breakdown in the areas of our national social life*” (*Ibid*).

In the past several years there has been a continuing trend of increased notifications of abuse and neglect to the department of Child, Youth and Family Services (Department of Child, 2005). The number of notifications requiring further action has also increased (*Ibid.*, p 11). In the twelve months to June, 2005, notifications reached 53,097, with 43,460 requiring further action (*Ibid*). During that period there were over 13,000 cases of confirmed abuse. It is estimated that 4-10 percent of New Zealand children experience harsh or severe physical punishment (New Zealand Health Strategy, 2001a).

We also know that the admission rates for children hospitalised for assault are probably not representative of the total number of child physical abuse cases. This is because many of the injuries that children receive “*are not treated and secondly, physical abuse of children often results in internal injury that is not visible*” (*Ibid.*, p 7). One in seven families within New Zealand experience family violence (*Ibid*).

New Zealand rated poorly in a recent UNICEF report that focused on child maltreatment deaths in rich nations (UNICEF, 2003). Out of thirty OECD member countries surveyed, New Zealand ranked in the bottom three, only ahead of Mexico and the USA. Although caution must be exercised in making comparisons between countries, especially where the cause of a child’s death is not entirely clear, we do know that the number of New Zealand children who die each year as a result of physical abuse, maltreatment and neglect is too high.

So what does this tell us about the lives of children? It tells us that for many children the family is one of the most dangerous places to grow up in (Benporath, 2003). Too

many children suffer too much harm by the very people who ought to protect them. Reflecting on Lafollette's proposal to license individuals before they become parents seems timely at the very least.

The parent who severely beats or neglects a child is clearly a poor parent and Lafollette is right to question their competence and suitability to have and look after children. As I have noted above, many children in New Zealand face violence within the family home, violence that is usually perpetrated by an adult member of the family. There is overwhelming evidence that the physical and psychological harms done to children result in serious consequences as Lafollette notes in his paper. But serious harm to children is not restricted to physical violence, abuse and maltreatment.

Children and obesity

New Zealand has a high prevalence of obesity compared with other OECD countries and obesity in both males and females is increasing at an alarming rate (Ministry of Social Development, 2005 p 33). Obese individuals are at increased risk for developing heart disease, hypertension and stroke, gallstones and some cancers (New Zealand Health Strategy, 2001b), as well as sleep apnea, a high incidence of orthopaedic problems, type 2 diabetes, non-alcoholic fatty liver disease, polycystic ovary disorder, asthma, increased intracranial pressure, hepatitis, and increased cardiovascular risk factors (Daniels, 2006). Many countries report an epidemic of childhood obesity (Reilly & Dorosty, 1999), (Wang, Ge, & Popkin, 2000), (Tremblay & Willms, 2000), (Livingstone, 2000), and overwhelming evidence shows that obese pre-pubertal children will become obese adults (Reilly et al., 2003), (Whitaker, Wright, Pepe, Seidel, & Dietz, 1997), (Freedman, Kettel-Khan, Dietz, Srinivasan, & Berenson, 2001).

Children who grow up obese suffer a number of serious harms, both to their physical and psychological health.

A recent review focusing on the likely consequences of childhood obesity concluded that *“pediatric obesity is likely to be a major cause of ill health in adulthood, but also that it contributes substantially to illness in childhood”* (Reilly et al., 2003 p 751). A further paper claims, rather alarmingly, that *“there are few organ systems that obesity does not affect in childhood”* (Must & Strauss, 1999 p S2). The authors report that *“few problems in childhood may have as significant an impact on childhood emotional development as obesity”* (Ibid., p S4).

Research clearly indicates that children are particularly vulnerable to obesity related health problems because their bodies are still in the process of development and growth (Daniels, 2006 p 48). Results of another study into childhood obesity suggest that *“obese adolescents are at greater risk for mistreatment by peers and may have fewer opportunities to develop intimate romantic relationships; this may contribute to the psychological and health difficulties frequently associated with obesity”* (Pearce, Boergers, & Prinstein, 2002).

Bullying, teasing, discrimination, victimization and aggression towards overweight and obese school children has also been confirmed by other studies (Janssen, Craig, Boyce, & Pickett, 2004), (Must & Strauss, 1999), as well as significantly lower levels of self-esteem (Strauss, 2005). Recently, it has been predicted that unless obesity levels significantly begin to reduce, the life expectancy of children and youth will decrease to a level below that of their parents. For the first time in humanity’s history, parents may outlive their children (Olshansky et al., 2005 p 1143).

Obese children quite clearly experience serious physical and emotional harm as a result of their being obese.

Children and second hand smoke

Children who live in households where people smoke are susceptible to a number of serious harms from second-hand smoke (SHS). These include respiratory illnesses, middle ear infections and decreased lung function. The authors of a New Zealand report conclude that each year there are:

- More than 500 hospital admissions of children under 2 years of age suffering from chest infections
- Almost 15,000 episodes of childhood asthma
- More than 27,000 GP consultations for asthma and other respiratory problems in childhood
- 1500 hospital operations to treat glue ear
- Approximately 50 cases of meningococcal disease (Woodward & Laugesen, 2001).

Research has shown that the SHS children are exposed to as a result of paternal smoking has a detrimental effect on “*children's pulmonary function. It causes infiltration of cells and hypertrophy and hyperplasia of mucus glands. Chronic inflammation of smaller airways may lead to bronchial obstruction*” (Bek et al., 1999).

Exposure to SHS is also linked to sudden infant death syndrome (Committee on Environmental Health, 1997), (Bergman & Wiesner, 1976), and may be linked to significant changes in the development of the foetal brain and nervous system (Slotkin,

1998). Adults who were exposed to maternal SHS as children before 10 years of age were also linked to an increased risk of leukaemia and lymphoma (Sandler, Everson, Wilcox, & Browder, 1985).

Children are passive smokers in environments where others smoke. They have no choice but to breathe in SHS, and as individuals whose physical development is in a process of development and growth, children are vulnerable to the detrimental effects smoking has on their bodies.

Clearly many children who live in smoky environments (and breathe in SHS) may be seriously harmed.

Children growing up in financial poverty²⁶

Children who grow up in financial poverty suffer from a number of serious harms. These include limited educational attainment, impaired productivity later in adult life, poorer health outcomes as adults, more hospital admissions, and disadvantages in cognitive development (G. J. Duncan, Brooks-Gunn, Young, & Smith, 1998), (McLeod & Shanahan, 1993), (Child Poverty Action Group Inc., 2005), (Korenman, Miller, & Sjaastad, 1995). UNICEF's recent report focusing on child poverty in rich countries paints a disturbing picture of children who live in poverty (UNICEF, 2005). It notes that *"there is a close correlation between growing up in poverty and the likelihood of educational under-achievement, poor health, teenage pregnancy, substance abuse,*

²⁶ As the UNICEF report rightly notes, there are many dimensions of poverty and an absolute measurement of poverty provokes controversy. Should it reflect an inability to buy the basic goods such as food, medicine and shelter? Or should it reflect circumstances where a child may be deprived of affection, love and resources because a parent has a drug or alcohol habit but their income is above that classified as a certain percentage of the medium income? Although complex, a definition of poverty (whilst related to time and place) is possible: *"a child is to be considered poor if the income available to the child, assuming a fair distribution of resources within the family and making allowances for family size and composition, is less than half the median income available to a child growing up in that society"*(UNICEF, 2005 p 7).

criminal and anti-social behaviour, low pay, unemployment, and long term welfare dependence” (Ibid., p 6).

A significant number of New Zealand children live in financial poverty. In 2002, 29% of children were living in poverty which means they lived in households with “*less than 60% of the median income net of housing cost*” (Ministry of Social Development, 2002), (Child Poverty Action Group Inc., 2005). Whilst the economy has improved significantly in recent years, the number of children living in poor households has increased. One powerful indicator of poverty within New Zealand (and no doubt elsewhere) is the meteoric growth in the number of foodbanks catering to families who do not have the financial resources to buy nutritious food (Wynd, 2005 p viii). It is worrying that despite improved economic growth, the use of foodbanks has not “*substantially diminished*” (Ibid), which suggests that many families are unable to adequately feed their children.

The serious harms that children suffer as a result of growing up in financially poor households are well documented, especially in the area of education. “*The lack of education achievement has a cascade effect on children's life chances because those who grow up poor have lower literacy rates, higher rates of dropping out, and higher delinquency rates*” (Risman). Children who have low literacy rates are more likely to become involved in delinquent and criminal behaviour than children who achieve literacy. Furthermore families on low incomes predominate in neighbourhoods that are “*characterized by social disorganization and few resources for child development*” (Ibid). We know that living in poverty has an adverse effect on children’s health as well as emotional and behavioural outcomes. “*Poor children suffer from emotional and*

behavioural problems more often than non-poor children, although these effects are less strong than the effect of poverty on educational achievement” (Ibid).

Clearly children who are raised in financial poverty may be seriously harmed.

Discussion

If we accept the claim that children are seriously harmed in many different ways as I have claimed above, then are we led to the same conclusion as Lafollette? Does my argument strengthen his position that if we are to protect children from serious harm we ought to license individuals before they become parents?

From a theoretical perspective, one could argue that widening our understanding of how children are seriously harmed may strengthen Lafollette’s claim that we should license all individuals who want to become parents. After all if we can show that children suffer serious harm in ways other than solely physical abuse, neglect and maltreatment, then we must also seek ways to prevent, or at least ameliorate that harm and protect children. Licensing may be the answer.

From a practical perspective, I suggest the answer is very different. Consistency is central to Lafollette’s argument. He states that licensing individuals before they become parents follows logically and coherently from the widely accepted premise that we ought to prevent harm to others. We license individuals in many different ways and whilst it may be inconvenient and disappointing for them to have to undergo testing, *“that does not diminish our conviction that we must regulate occupations or activities that are potentially dangerous to others”* (Lafollette, 1980 p 184). Therefore in order to be consistent we must ask; what harms may result overall if we take into account the broader notion of serious harm that I discussed above: that is, we consider not only the harms suffered by obese children, those living in smoky environments and those who

live in poverty, but all individuals who desire to become parents? What are some of the practical implications of licensing?

Once we broaden our conception of serious harm, as I suggest we must in order to be consistent, we will see that the practicalities resulting in a licensing program such as Lafollette's are extremely problematic. I suggest there are three groups of individuals who will be seriously harmed by licensing: those who will be denied a license to parent because they are considered incompetent, those who are licensed but will have their children removed from their care if they have (later) been judged incompetent to parent, and finally the children themselves.

The Serious Harms of Licensing:

Individuals considered incompetent to parent

Lafollette proposes that a licensing program will be relatively simple to construct and implement. It would not have to be 100% accurate, and demands on the tests would not be unreasonable because we do not demand unreasonably high standards from other forms of licensing. The licensing test is also predictive in nature therefore we must be reasonably certain that the serious harms to children are likely or probable²⁷. Those who failed the test could easily re-sit their test (several times if necessary). We are not concerned, Lafollette notes, with "*picking out good parents*", rather we want to be able to identify bad ones – "*those who will abuse or neglect their children*" (*Ibid.*, p 190). His criterion for deciding what a bad parent might be like includes;

- Those individuals who were prone to violence and abuse, easily frustrated or unduly self-centered (*Ibid.*, p 191)

²⁷ It is unlikely we could ever accurately predict with absolute certainty who would seriously harm their children and those who would not, therefore a reasonable degree of accuracy is acceptable.

- Those individuals who were themselves maltreated as children (*Ibid*).

As I noted above, such a licensing proposal is predictive in nature. Individuals will be tested on the likelihood of them seriously harming their own children. Lafollette is right to assume that we do not want parents physically abusing and maltreating their children. If we can weed incompetent individuals out of the process until we are assured they are no longer a threat to any future children they may have, we can be reasonably confident that children are protected from serious harm. But who else will licensing weed out? If we are sincere about reducing or ameliorating serious harms to children and committed to moral consistency, we will also have to weed out those individuals who are already obese, or those overweight and prone to obesity because they are likely to produce obese children. It will also comprise those who smoke because we know that living in a smoky environment and breathing in second hand smoke seriously harms children. It will also include those individuals who are poor because growing up in poverty increases the likelihood that children will suffer from a range of serious harms that may adversely affect them for the rest of their lives.

The number of individuals who will be prevented from becoming a parent (denied a license) must surely increase when we recognise that children are seriously harmed in these different ways. Presumably once an individual had lost weight and managed to keep it off for a determined period of time she/he may be granted a license. The individual who can show she/he has successfully stopped smoking may also gain a license. The poor individual who can show that their financial circumstances have improved may also gain a license, all things considered.

There is another important point to make about licensing individuals before they become parents. When I sit my driver's license I am being tested and assessed on my

performance as a driver now, whereas a licensing test to become a parent now predicts my future performance as a parent. If I fail my driver's license I may be annoyed but I can still get around town by relying on friends or catching public transport even though I may be inconvenienced. The failure to gain a license only says to me that I failed to grasp some aspect of driving at the time I took the test. It says nothing about me as a person generally in the way that being denied a license to have a child does. If I am denied a license to have a child it implies that I am a failure at participating in something that is deeply human, no matter how many times I am eligible to re-sit the test. It is also predicting my future performance as a parent, something that cannot easily be assessed in a test no matter how detailed it may be. As "*the desire for children is among the most compelling motivations in human behaviour*", we ought to be concerned about proposals that seek to prohibit such a deeply human activity on the basis of an assessment that determines my future performance as a parent (Blustein, 1982 p 246).

There is another worrying implication of Lafollette's licensing program. If it can be shown that certain groups of people are predominantly over-represented in poor communities or that particular kinds of individuals are prone to obesity, licensing could be used to prevent these kinds of people from becoming parents. Licensing could be used as a way of prohibiting individuals – those who are considered 'undesirable' – from having children. We should be very cautious in preventing individuals from parenting on the grounds that they 'seem like the kinds of people who harm their children', as this is a clear violation of their liberty. Yet this is a probable consequence of a licensing proposal such as Lafollette's because it is predictive in nature.

Is there clear evidence that shows certain individuals are more likely than others to seriously harm their children? There is strong evidence to show that social factors such as poverty, overcrowding, lack of education and the age of the mother (where she is very young) contribute to child abuse and neglect (Weatherburn, Lind, & Ku, 1997), (Child Poverty Action Group, 2003), (Davies, Wood, & Wilson, 2003), (Aber, Bennett, Conley, & Li, 1997), (G. J. Duncan & Brooks-Gunn, 2000). We also know that unemployment and low income are clearly associated with child abuse referrals (J. Taylor, Spencer, & Baldwin, 2000). Of course we know that this is only a statistically significant correlation (i) parents can be poor, uneducated, very young and competent, and (ii) well-off, educated and lavishly housed, in their 20's and 30's and still be guilty of cruelty and various forms of child abuse.

Such evidence tells us more about the social circumstances that individuals are living in than the type of individual who is abusing and neglecting their children. If the prevalence of these social factors are reliable indicators at predicting abuse they assign at least part of the responsibility away from parents (This is particularly the case with financial poverty which may not be the sole responsibility of the parents – for instance, the sudden death of the breadwinner in a family). It seems obvious that we ought to address these factors first and then look at the child abuse figures before we think about a licensing procedure because only then can we properly assign responsibility to parents.

Removing children from incompetent parents

A licensing program does not end with the granting of a license to a successful applicant. Licensing gives authority not only to prevent individuals becoming parents, but to remove licenses from parents who are later judged to be incompetent: that is it

gives authority to remove children from those parents who are considered incompetent to parent.

Activities and occupations that require licensing take seriously those members who through incompetence or disregard for the rules bring the vocation into disrepute. As a result of misconduct or incompetence individuals may be fined, required to undergo further training or examination, or lose their license to practice. In particularly serious cases of misconduct or incompetence, individuals may face the full force of the legal system.

Under Lafollette's licensing system some kind of monitoring system will have to be implemented whereby parental competency is routinely assessed. Perhaps this would be no more rigorous than the system we currently have in place now that detects and responds to the abuse and maltreatment of children.

However, being a parent is significantly and relevantly different from being a doctor, lawyer, pharmacist or teacher. As I noted previously in chapter three, parenting is not an occupation or activity like any other role we may occupy or carry out. Not only are parents unable to just change their minds about maintaining their role, it is a 24 hour, 365 day a year role, at least while children are young. We simply cannot leave behind the obligations and responsibilities of parenting when we decide we have had enough, or if the daily grind of the job bores us. Whereas the professional can leave behind the obligations associated with being a teacher or doctor after eight or nine hours work, parents cannot leave behind the obligations that go with being Mum or Dad. The role of being a parent cannot be relinquished during a busy day whereas the obligations I have in my role as a teacher, for example, can be relegated to my colleagues if the need arises. Therefore it would seem sensible, in the first instance, to implement strategies

that support families with children rather than a punitive system that punishes them. Of course we must remove those children (from parents) who are being, or are likely to be seriously abused and neglected. However a system that routinely monitors all parents and children should be a last resort as it implies incompetence from the start.

When a licensed doctor or lawyer proves incompetent and their license is revoked, this may sometimes lead to the break-up of their family, *if* they have one. But if a parent loses their license, the break-up of the family would be, under the proposal inevitable. And family break-up is usually a serious harm, particularly to the children.

Punishing the children

Of course there are some parents who make their children's lives a misery. Suppose we assume, on Lafollette's behalf, that being taken away from parents who sexually abuse or severely neglect them is not a serious harm to children, but something they welcome. Indeed not to remove children from such parents would be to perpetrate the serious harms further. The case will be very different when children are taken away from parents who are making them obese, destroying their health with SHS, or harming their educational opportunities as a result of living in poverty. From the child's point of view, this is all fine. It's ordinary home life, with their beloved Mum and Dad and to be taken away from it would be devastating for them. The involuntary trauma of parent/child separation is surely deeply traumatic.

According to Lafollette children who are the victims of physical abuse and neglect may be taken from their parents and put up for adoption (*Ibid.*, p 193). Lafollette contends that this would not "*punish parents at all*" (*Ibid.*). Would he advocate the same treatment for parents whose children suffer from the other kinds of serious harms that I have suggested are significant? Lafollette implies that competent parents will not

physically abuse, neglect or maltreat their children. Applying consistency, he will also have to admit that competent parents will not smoke around children in their homes or in their cars, grow obese children, or be unfortunate enough to be poor.

However taking children from parents punishes both the parents and children.

Lafollette's claim that removing the children from inadequate parents and putting them up for adoption wouldn't punish parents at all ignores the very real and traumatic harms that were traditionally done to many women (and their children) who had children outside the context of marriage and were forced to give them up to others. Even if Lafollette did not advocate adoption but rather supported placing children into foster care (until the parents had satisfied authorities that they were fit to parent), removing children who are born to incompetent parents punishes them and their parents and Lafollette is wrong to think otherwise. Taking children from parents, who smoke, are overweight, or poor inflicts serious harm on them all, but primarily on the children who will be forced to leave the parental home. For some children this may mean being placed with strangers.

The impracticalities and impermissibility of licensing

The group of individuals who will be denied a chance to parent until they are competent, that is, until they are within a normal weight range, have stopped smoking, or have improved their financial situation, has grown considerably. In fact it is fair to say that a significant number of the New Zealand adult population will not gain a license and so will not be permitted to have children. As the number of overweight and obese and poor individuals is increasing, the group of non licensees' will only increase.

I claim that the large number of the population who will not gain a license to parent, or who will have their children removed from their care cannot be justified. This is not

because these harms are any less serious than the harms of physical abuse, neglect and maltreatment, or that obesity and smoking and poverty related harms are somehow relevantly different to the harms Lafollette documents. They may all adversely shape the lives of children who are affected by them and we must be serious in our efforts to ameliorate or reduce them as we have an obligation to prevent children from being harmed. Rather, we cannot justify licensing individuals because the measures necessary to detect incompetent individuals (from becoming or continuing to be parents) results in far greater harm to them and their children than the benefits that may result from licensing. Such measures will entail monitoring families in far reaching ways. It will not just necessitate keeping any eye on families who are known to child welfare agencies (those families who have been reported to the authorities by concerned individuals), but the active involvement of all members of society. People will surely be encouraged to report children who are suspected of being seriously harmed by being obese, poor and the victims of SHS inhalation. Whilst physical abuse and maltreatment may be difficult to detect, most people recognise a severely overweight or obese child, and we can smell cigarette smoke on children or ask them directly if smoking occurs in their homes (detecting a child who lives in poverty may be as difficult as recognising a physically abused child). This may result in a monitoring system having to be particularly meticulous and rigorous.

I have claimed that if we widen the notion of serious harm as consistency demands, such a licensing program may achieve its purpose but at a social cost that far outweighs the benefits to children. I argue that it will result in far greater harms both to children and parents.

Alternatives to licensing

Central to Lafollette's argument is that children ought to be protected from serious harm; however I have argued that we do not need licensing to protect them from it.

There are many far less intrusive ways of protecting children.

Lack of education is one factor that does play a part in the incidence of child abuse, neglect and the harms associated with poverty, smoking and obesity. It would seem that educating young persons about the responsibilities and demands of becoming parents would be valuable in helping to prepare them for their own futures, regardless of their intentions (or not) to have children.

In New Zealand, the Christchurch Early Start Initiative has been operating since the mid 1990's with considerable success in supporting families marked by a wide range of disadvantages and difficulties including socio-economic disadvantage, family conflict and instability, impaired child rearing practices, limited childhood experiences and restricted life opportunities (Ministry of Social Development et al., 2005). The home visitation program identifies at-risk families (primarily through Plunket nurses) and *"comprises a system of home-based family support and visitation provided by trained family support workers"* (Ibid., p 16). A summary of the findings of a randomised trial noted that the *"weight of the evidence suggests the Early Start program delivered small but consistent benefits in a number of areas, namely, child health, early childhood education parenting behaviours, child abuse and neglect, and child behaviour"* (Ibid., p 108).

In the United States there are programs operating in many high schools that educate students about parenting and the skills required to be a good parent (Schonberg, Anderson, Bays, & Duncan, 1998). There are also programs that link up very young

mothers with older women who have had families so that the older women can support and help young mothers with any concerns and problems they may have (Olds & Kitzman, 1990).

We also need to educate children and adults about the quality and quantity of food they consume²⁸ as “*underlying the obesity problem is widespread inertia amongst a population that fails to see a problem relating to themselves or their family*” (Eagle, de Bruin, & Bulmer, 2002 p 12). The prevalence of obesity among children in New Zealand has increased markedly over the past two decades and the consumption of fast-food²⁹ and junk food³⁰ is directly related to this increase (although it is not the only factor that accounts for the rise in obesity). A recent US study concluded that “*on a typical day that fast-food is eaten, children consume substantially more total energy and have worse dietary quality compared with a typical day without fast-food*” (Bowman, Gortmaker, Ebbeling, Pereira, & Ludwig, 2004 p 117). They noted that children who ate fast-food consumed more kilojoules than children who did not and that this impacted negatively for their future weight.

Whilst educating individuals about healthy eating habits is crucial if we are to seriously address our obesity problems it is not enough on its own. We also need to implement more programs that get children excited and enthusiastic about activity and exercise both at school and beyond.

²⁸ At the time of writing, the New Zealand government is looking to implement an extensive physical education review of children’s activity levels in schools. One suggestion proposes to increase children’s physical education to one hour per day. Many school cafeterias are changing to more healthy food options and the sale of high sugar, carbonated drinks are restricted or banned. In April 2006, the Advertising Standards Authority issued extensive guidelines on the ways in which food and beverages are to be advertised to children. “*Advertisers now cannot use persons, characters, or groups who have achieved celebrity status to promote food in such a way so as to undermine a healthy diet. Treat foods directed at children should not actively encourage children to eat or drink them inappropriately or in excess*” <http://www.asa.co.nz/Final%20Report%20codes%20review%203%20April%202006.pdf>.

²⁹ Fast-food refers to those foods that are inexpensive to prepare and are served quickly.

³⁰ Junk-food refers to foods that are high in calories but have minimal or poor nutritional value.

Of course these suggestions would all require tax-payers money. But, as I argued in chapter three, we all have demanding obligations to the children in our society who are not our own. This surely includes the obligation to protect them from serious harm if we can, and if instituting such practices is what it takes, we are under an obligation to promote, support and pay for them.

A further suggestion would be to implement compulsory courses that individuals must attend which instruct individuals about the reality and demands of parenting, and the skills necessary to raise a child, particularly when expecting one's first child. The compulsory aspect does raise important questions about interfering with individual freedom as they entail an infringement of liberty. Such courses are justified, I believe, because they will only apply to those who are expecting a child and not to everyone, (which seems to be a consequence of Lafollette's licensing), and their focus is on educating individuals rather than predicting who might harm subsequent children. In this case, liberty loses out to probable harm. The infringement (of liberty) is nothing like as great as what Lafollette proposes with his licensing of parents.

Another option would be to reintroduce the family benefit payment, but only for those who successfully complete a parenting skills course. In this way individuals are given a financial incentive to gain valuable skills and it also sends out a clear message to society that parenting skills are recognised as valuable and important in the upbringing of children.

We need to acknowledge the pressures and stresses that many families face and seek to find ways to strengthen those relationships and reduce those pressures, rather than focusing on punitive measures such as the one Lafollette advocates. It is worth noting

that although we consider parenting an important adult responsibility, we assume and expect that individuals will undertake it with little support and no training whatsoever.

Conclusion

In his paper Lafollette considers the serious harms children suffer at the hands of their parents. It is appalling that in many countries that claim to value and cherish children, individuals continue to have children they abuse and neglect. A licensing program, argues Lafollette, addresses the serious harms done to children by preventing individuals becoming parents when it is predicted that they are likely to seriously harm them. Furthermore individuals who have children whom they go on to seriously harm stand to lose their children (and their licenses). Lafollette claims that a licensing proposal is both theoretically and practically sound.

In this chapter I considered the notion of serious harm and the implications that follow if we apply consistency. I claimed that this must entail widening our understanding of serious harm if we are to capture what truly harms children. However, rather than strengthen Lafollette's argument for licensing, I argued that such a proposal could not be justified because of the serious harms that would eventuate: they are simply too great. If as Lafollette suggests, we can reasonably predict those who are likely to harm any future children they may have, (and thus justify refusing them a license on such grounds) consistency demands that we refuse to license those individuals who are obese, smokers and poor. Licensing does not stop there. Individuals who have successfully gained a license will be routinely monitored and stand to lose their children if it is predicted that they may be seriously harmed in the future. Children will be separated from their parents and families broken up.

Although LaFollette is right to question the competence and suitability of individuals' to parent well, his licensing proposal cannot be justified. However we must address the serious harms that are done to children and seek ways to ameliorate them. My discussion concludes however that licensing is not the answer.

Concluding comments

Children are special members of the moral community who possess unique moral status. They are special because of certain features about them; they have certain fundamental needs, they belong to us, they are the future and they are vulnerable. When seen in combination with the fact that they will grow up and leave childhood behind, the ways in which children are treated has profound significance, not only for the adults they will become, but for all members of society.

In this section of my thesis I began by critically reflecting on the intuition that children have special moral status within the moral community and are deserving of certain kinds of treatment that we generally do not extend to those who are not children. I then considered two different accounts of why children have moral status and the obligations owed to them; that they are sentient beings and that they are rights-holders. I concluded that whilst both offer important insights into why children matter; neither goes far enough in capturing what is special about children. Neither account does justice to the complexities and uniqueness of children's lives. Consequently I began to develop an account of why we have the obligations to children that we do. I claimed that children are owed demanding obligations from others because of certain characteristics of them; they have important fundamental interests, they are vulnerable, they are the future and they are ours.

Of course we cannot focus exclusively on the lives of children and what is owed to them without looking at the context of the families in which children live, specifically

the role parents play in ensuring the child's flourishing and the nurturing of their autonomous capabilities. It is clear that being a good parent is crucial to the successful development and flourishing of children; quite simply without good parents, children would not mature into the decent, autonomous individuals we want and need them to be.

Looking more widely at the lives of children generally we cannot ignore the influences and authority adults have over children who are not their own, and neither can we ignore the interest we all have in the wellbeing of children generally. The lives of children are a community's responsibility and concern, thus it is important to consider what obligations we have to children who are not our own.

Finally I considered a very practical issue that arises in the context of parenting; if we agree that the parental role is a very important one in the raising of decent, moral children, ought we to license individuals before they become parents? In the past several decades many commentators have called for a system of licensing that would restrict the reproductive capabilities of individuals because of the serious harms many children experience throughout their young lives. LaFollette's licensing proposal requires that those who want to become parents would have to pass a test designed to ensure only those who were competent could go on to parent. Although licensing seeks to offer a way of determining competent ('good') parents from incompetent ('bad') parents, I claimed that the serious harms eventuating from such a punitive system would outweigh any benefits to children. Importantly, this discussion highlights not only the obligation we have as both parents and members of society to prevent children suffering serious harms, but children's vulnerability.

The purpose of the discussion in this section was to situate children clearly in the moral community. I have claimed children must be recognised as individuals possessing unique moral status, who are members of families in the wider community and future citizens whose well being is crucial to the flourishing of society. They are individuals but they are intimately connected to others as well. As parents and other adults, we have demanding obligations to children that we do not have to any other group in quite the same way. Viewing children in this way is important, especially if we are to consider them in relation to predictive genetic testing.

So where are we now? The goal of good parents is to facilitate and nurture their children's autonomous capacities and abilities so that they become decent human beings who can lead independent, successful lives and who can contribute to the good of society. Central to being a parent is enabling one's children to become autonomous individuals. This involves, as Blustein notes, "*the kind of affectionate, appreciative and supportive upbringing that gives them a sense of their own value and a confidence in their abilities to fulfil their intentions*" (Blustein, 1982 p 128). This entails fulfilling a number of obligations to children, such as the obligation to ensure children's health and happiness. Ensuring children's health and happiness is directed towards the end of the child's becoming an autonomous adult.

What can we take from this discussion into the next section that focuses on genetically testing children for adult onset diseases?

- Children are special members of the moral community with unique moral status, whose lives have significant import for us all. This is because they have a number of fundamentally important needs that are unique to them. We are

obliged both as parents and other adults to seriously consider our treatment of them.

- Children have a fundamental interest in becoming autonomous individuals. We have an obligation (both as parents and other adults) to facilitate and enable this developmental process.
- Society has an obligation to ensure that families are supported in nurturing their children to become decent, autonomous individuals.
- As parents and adults we have an obligation to ensure that children are not seriously harmed.
- When we focus on children's lives, we cannot isolate them away from the family context in which they live. Whilst they ought to stand centrally in our deliberations, we must also reflect on the wider family interests.

These conclusions recognise the unique moral status children have in the moral community of which we are all an important part and provide a framework for addressing the issues, questions and concerns that arise in the second section of this thesis.

Section 2 introduction. Predictive genetic testing of children for adult onset diseases: some ethical implications of testing

“We are living in a time of breathtaking progress in human genetics. This is the genomics era – the time when the DNA sequence of the human genome has been almost completely determined, the time when the functions of thousands of human genes in health and disease are being analysed. It is the time when the study of small variations in many genes will lead to individualised medicine, the time when the genetic basis of most congenital abnormalities will be revealed, and the time when comparison of human and other primate genomes will reveal the basis of human uniqueness. This is the time of endless excitement for those who participate in the discovery process, either directly in research or indirectly by application of the torrent of new knowledge in the health professions” (McConkey, 2004 p 1)

Background

Now that the goal of mapping and sequencing the human genome as a result of the Human Genome Project has been completed, the implications of the knowledge we have gained so far, and that which is still to be discovered will be far reaching. We will gain important knowledge that will aid strategies in regard to the prevention and treatment of diseases. It also has the potential to change the ways in which we understand, diagnose, predict and treat certain diseases. This is for several reasons.

New technologies will allow more accurate genetic testing and more accurate risk assessment of genetic disorders both in adult and childhood. As we learn more about the function of genes, their relationship with environmental factors and their correlation to disease, technology will allow testing for disorders that we were previously unable to

test for. The technology will also be able to diagnose more common diseases and has the potential to change the way in which we approach medicine (pharmacogenetics, screening populations and genetic counselling).

Identifying individuals who carry faulty genes has been possible for many years without molecular genetic technology. Ultrasonography of at-risk individuals can accurately determine that an individual has cysts on the liver and kidneys, leading to the likely diagnosis that she/he has polycystic kidney disease. Individuals who carry haemoglobin disorders can be identified by routine haematological analysis (Clarke et al., 1994). With the recent advances in molecular genetics, individuals of any age can now be tested for a large range of inherited disorders, without the need for “*the at-risk person manifesting early signs of the disorder*” (Ibid).

A person’s genetic makeup can be ascertained in several different ways: “*DNA analysis, RNA analysis, biochemical/protein analysis or some form of presymptomatic detection of merging pathology based on anatomical or functional changes*” (Pembrey, 1996 p 72). DNA analysis reveals genetic information by directly examining the DNA molecule itself and scanning it for mutated sequences. Inferences can then be made from the knowledge that comes from scanning the sequences. Genetic tests of this kind may be carried out for a number of reasons: Carrier screening; pre-implantation genetic diagnosis; prenatal diagnostic testing; newborn screening, predictive genetic testing for adult-onset disorders such as Huntington's disease; pre-symptomatic testing for estimating the risk of developing adult-onset cancers and Alzheimer's disease; confirmational diagnosis of a symptomatic individual; and forensic/identity testing (National Health and Medical Research Council, 2000) .

Knowledge about one's genetic inheritance can be both burdensome and beneficial for individuals and families. For instance, knowing that a disorder is manifest within the family allows individuals to consider pre-implantation genetic diagnosis (PGD), in conjunction with in-vitro fertilisation (IVF) to avoid having children with serious genetic diseases such as Tay Sachs, cystic fibrosis and chromosomal abnormalities such as Down's syndrome (Trisomy 21). Embryos that are shown to carry certain genetic mutations or chromosomal abnormalities may not be implanted into the womb, thus ensuring that any resulting children born will be free of the disorder. Prenatal diagnosis (PND) detects the presence of a genetic abnormality in a foetus and is commonly done by amniocentesis or chorionic villus sampling. Despite these technologies allowing individuals and couples beneficial options about their reproductive choices, both PGD and PND raise ethically challenging questions: the former about those embryos that are not implanted (are they discarded, should they be used for research purposes?) and for PND, the troublesome issue of selective abortion.

Other ethical concerns highlight issues of privacy and confidentiality of genetic information (for instance, should third parties be entitled to know genetic information about me; how will such information be stored, who will have access to it, and how might it be used?). Some commentators predict that these technologies will result in a slippery slope scenario; *"it will likely become possible for patients to request prenatal testing and abortion not only for serious diseases but also relatively mild diseases, late-onset diseases, treatable diseases, elevated risks for common diseases, and eventually non-disease characteristics, such as height and body build"* (Strong, 1993).

It is estimated that single gene disorders account for some 4000 severe inherited diseases³¹. Currently over 900 genetic tests are available, with the anticipation that this number will rise dramatically as the functions of genes are discovered and testing technology improves both in accuracy and scope (Human Genome Project Information, 2004). *“New disease genes are mapped and characterised at an increasing rate, and simpler, cheaper methods are being developed for genetic testing and screening. This will inevitably lead more patients, relatives and pregnancies to be tested”* (Jarvinen & Kaariainen, 1998 p 91).

It is perhaps inevitable that as more adults become aware of genetic tests available - through media coverage, the recommendation of their doctor, through advertising from biotechnology companies (those who offer genetic testing over the internet) or an awareness of others who have been tested - individuals who perceive themselves to be at risk, will request testing for themselves and for their children. This will also happen as the tests become cheaper to administer. Clinical geneticists and counsellors report that parents are requesting that their children be tested when a disease has a known family history (Harper & Clarke, 1990), (Michie & Marteau, 1996). In New Zealand, demand for genetic testing is increasing (National Advisory on Health and Disability, 2003).

Genetic testing of children

Genetic testing of children falls into the following four types of situations;

1. Tests that provide immediate therapeutic or preventive benefits to the child.

In all western and many non-western countries newborn babies are tested for a number of conditions for which effective, immediate treatment or prevention is available. In

³¹ <http://www.dnapolicy.org/genetics/geneticsAndDisease.jhtml>

New Zealand, newborn babies undergo the 'Guthrie' test (usually around the second day of life) and are screened for a range of genetic diseases from blood taken from a heel prick. These include; phenylketonuria, maple syrup urine disease, biotinidase deficiency, cystic fibrosis, congenital hypothyroidism, galactosaemia and congenital adrenal hyperplasia (Ministry of Health, 2004). For instance, in the case of phenylketonuria, dietary measures are initiated very early in infancy to prevent mental retardation. Testing to detect these seven diseases is routine and voluntary in New Zealand, with almost 100% of newborn infants being tested as part of the national screening program (Privacy Commissioner, 2003).

Testing children for childhood onset diseases such as familial polyposis coli (where removal of the colon in early adolescence is often necessary to prevent cancer) and familial hypercholesterolemia (where diet and medication reduce cholesterol levels) confer direct benefits to those tested (Wertz, Fanos, & Reilly, 1994). These tests are not part of routine newborn screening tests but may be performed where a child is at risk and a family history (of the disease) is known.

2. Tests that provide genetic information about the carrier status of an unaffected minor.

Such tests (often referred to as carrier testing) determine whether or not an individual has a mutated gene or chromosomal abnormality which will not affect the person's health but increases his/her chance of having children with the disorder in question (National Health and Medical Research Council, 2000). Testing entails identifying individuals who carry one copy of a gene for a disease that requires two copies for the disease to be expressed. These include conditions such as: cystic fibrosis, fragile X syndrome, sickle cell anaemia, Tay-Sachs disease and muscular dystrophy (American

Academy of Pediatrics, 2001). Carrier testing can permit informed reproductive choices but remains controversial (in the case of testing young children) because of concerns over privacy of personal information: *“if an infant or child is tested for carrier status, and the result is known to parents and possible other family members, the right to autonomy over information personal to them has been removed”* (Canadian Paediatric Society, 2003). Testing for carrier status may be performed on sexually active adolescents who are considering having a child. In the case of adolescents, a request for testing should come from them as they are the primary decision makers (Lessick & Faux, 1998).

3. Testing is carried out on a child solely for the benefit of another individual within the family

“This occurs in DNA linkage analysis where several members of a family, both affected and unaffected, must be tested in order to find out whether a particular individual (or a foetus) has a gene” (Wertz, Fletcher, & Berg, 2003 p 59).

Testing of this kind is generally carried out in order for parents to use prenatal diagnosis in any future pregnancy. The child gains no medical benefit from such testing.

4. Predictive genetic testing (PGT) of currently healthy children and adolescents for adult onset disorders (single gene or monogenic disorders).

Testing is *“performed on a person who has no symptoms of a specific disorder at the time of testing, to determine whether or not he/she has a mutant gene”* (National Health and Medical Research Council, 2000). Such tests do not provide medical or preventive benefits to the child. At the time of testing, children are healthy and do not exhibit any

symptoms of the disease, however it is almost certain that the disorder will develop in the future if the genetic mutation is detected. Genetic testing of this kind is morally problematic and controversial. It is this area of genetic testing that I will be focusing on in this section of my thesis.

The specific ethical arguments and implications of PGT of children for adult onset diseases raised within the bioethical, legal and medical literature are the central focus of this section of my thesis. I should make it clear from the outset that my primary focus is on single gene mutation disorders (autosomal dominant³²) that have more or less total penetrance and are currently untreatable and unpreventable. This means that if you have the genetic mutation you will almost certainly go on to develop the disease unless you die of something else beforehand. These disorders include; Huntington's disease (HD), autosomal dominant polycystic kidney disease³³ (PKD), and myotonic dystrophy. Some familial breast cancers (that are autosomal dominant) may have reduced penetrance, but still confer a very high risk of developing breast cancer on those who carry the mutation. These conditions are different to those that are multifactorial in origin (polygenic); that is, the development of these multifactorial disorders is dependent on both genetic and non-genetic factors (it is their combined effect that is important).

The process of informed consent, free from coercion allows the genetic testing of autonomous adults in an empowering manner. Conversely the genetic testing of young children raises a number of ethical challenges. In the following discussion I will set out

³² Autosomal dominant inheritance means that the gene involved is not on one of the sex chromosomes and so males and females have the same chance of being affected. It also means that a person only needs to have one changed gene before they have the disorder. The normal gene is not able to make up for the gene with a change in it.

www.ucdmc.ucdavis.edu/children/services/cleft/health/anomalies/glossary.html

³³ Currently a diagnosis of polycystic kidney disease is made through ultrasound testing and not a genetic test, however I have included it in my discussion because parents may request that their at-risk child is tested for the disease and many of the ethical issues about testing and disclosure are the same.

the ethical issues that arise in the area of genetically testing children for adult onset diseases.

Requests for children to be tested for adult onset diseases may be made for a number of reasons:

1. Parents who are considering adopting a child may be interested in knowing the genetic status of a child they are considering adopting, and there is evidence that some individuals and agencies have sought pre-adoption genetic testing in the case of Huntington's disease (Morris, Tyler, & Harper, 1988), (Bloch & Hayden, 1990). An adoptive parent may claim a right to know whether a child has inherited a genetic disease (such as HD) before committing to adoption (Bloch & Hayden, 1990). However it is argued that, *"testing any child before adoption sets a dangerous precedent that could make it more difficult to find homes for children at risk in the future. In other words, testing one child could lead to testing many more, if families become aware that those responsible for adoptions will accede to their requests"* (Wertz et al., 2003 p 61). The view that adoptee children not be tested for adult onset diseases (as a condition of adoption) is widely accepted in the literature (Bloch & Hayden, 1990), (Morris et al., 1988), (Wertz et al., 2003), (American Society of Human Genetics Social Issues Committee & American College of Medical Genetics Social, 2000). Such testing may also imply that the child is a commodity *"undergoing quality control"* (Wertz et al., 2003 p 60).

2. Parents may want their at-risk child tested to relieve their own uncertainty and anxiety over not knowing if their child carries the genetic mutation for a particular disease that is present within the family.

3. Parents may request the testing of their child to assist them in their (parent's) own reproductive decisions concerning future children (for instance, in the spacing and number of subsequent children). A parent may reason that were a child to return a positive test result (the genetic mutation was detected), in the future, they would undergo PGD and IVF to eliminate the worry of having another affected child. Or they may decide not to have any more children of their own and instead consider other ways of creating their family.

4. The child may request testing for herself. This may arise when a child sees family members with an inherited disease and wonders if she also carries the disorder herself.

5. Parents or caregivers may request testing of their young children in the sincere belief that such information and knowledge would be in the best interests of the child and the family. A parent may claim that having the children tested may confer direct benefits to both the children and family in the way of increased family cohesion, the resolution of uncertainty, and the opportunity for parents to consider how best to inform their children over a period of time (it gives them time to plan how best to disclose such information to their children).

Despite requests from parents and children, there is a general international consensus amongst genetic service providers and professional genetic societies, that PGT of children for adult onset diseases should not be undertaken (Human Genetics Society of Australasia, 2003), (ASHG/ACMG, American Society of Human Genetics Board of Directors, & Directors, 1995), (International Huntington Association, 2004), (American Academy of Pediatrics, 2001), (National Society of Genetic Counselors, 2003), (Huntington's Disease Society of America, 1994) . There are two broad justifications given for this position: First, it is claimed there are no clear and defined medical

benefits to the child from being tested in the event he or she tests positive for a mutation, and second, that such testing is likely to result in serious harm to the child. Consequently it is claimed that, “*if no clear benefits exist, parents should restrain their desire to know and professionals should not yield to their request*” (Wertz et al., 2003 p 60).

Within the bioethical literature the prohibitive stance of those various professional communities has been widely supported, criticized and called into question (Bloch & Hayden, 1990), (Davis, 2001), (Clarke et al., 1994), (Cohen, 1998), (Michie, 1996), (Harper & Clarke, 1990), (Hoffmann & Wulfsberg, 1995), (Wertz et al., 1994), (Michie & Marteau, 1996), (Robertson & Savulescu, 2001), (Burnside, 1997), (Dickenson, 1999), (Malpas, 2005b, 2006), (Wexler, 1992), (R. E. Duncan, 2004). It has been claimed that the benefits to children and their families from PGT have been too narrowly construed and that children may stand to benefit from the knowledge that comes from a predictive genetic test (Robertson & Savulescu, 2001) .

Arguments justifying a prohibitive stance (current policy) in regard to PGT:

Those who support prohibiting the testing of children for adult onset diseases on the grounds that such testing is likely to result in serious harm to the child claim the following three reasons as justification:

1. Testing children may violate their future autonomy. That is, it violates the future adult's autonomous choice not to know genetic information about herself.
2. Risk of invidious discrimination and stigmatization if genetic information is known about an individual; specifically in the areas of insurance (life, health and disability), employment and access to healthcare. Related concerns surround the breaching of

patient confidentiality and privacy of genetic information (for instance; who will have access to the child's genetic information, how will it be stored, and will the sample be used for any other purposes such as determining paternity?)

3. Children may experience serious psychological harm if tested (particularly, though not exclusively if they test positive). These harms include;

- Lowered expectations within the family
- Damage to the child's self-esteem
- Adverse effects on the child's capacity to form future relationships
- A positive test result may reinforce already latent feelings of unworthiness
- 'Vulnerable child syndrome'
- The individual may feel doomed about her future
- Parents' attitudes towards the child may turn towards disappointment or rejection
- 'Survivor guilt'
- Anxiety may be generated by the child's genetic status when it is known that the child will develop the disorder. The anxiety may cause worse problems than continued uncertainty.

At the present time nothing can be done to medically benefit the child (either a therapeutic or preventive benefit) who is known to carry a genetic mutation for an adult onset disease, and a clear and defined medical benefit to the child is a paramount

consideration (Human Genetics Society of Australasia, 2003). Thus we ought not to genetically test children for these diseases.

Arguments justifying a supportive stance in regard to PGT

Some commentators have claimed that the putative harms that may result from such tests are inconclusive because of a lack of empirical evidence (Michie & Marteau, 1996), (Michie, 1996). Others claim that “*current guidelines construe benefit too narrowly*” (Robertson & Savulescu, 2001 p 49). A number of benefits may result as a consequence of testing children for adult onset diseases. These include:

- Enabling and facilitating the child’s developing autonomy by encouraging her to make decisions about her life as she grows and matures with the knowledge that comes from testing
- PGT allows the child to adjust to the circumstances whilst she is young and her plans for the future are not settled or formalized
- The fostering of openness within the family
- The resolution of parental and family uncertainty
- Parental expectations for the child’s future can be more realistic
- Recognition that disease is but one part of who we are and the lives we lead, and that we all carry “*faulty genes*” (Clarke, 1998), (Wertz, 1998).

Once we have thoroughly considered the ethical arguments both for and against testing, then we can make reasoned claims about the permissibility (or not) of testing children for adult onset diseases.

Chapter summary of section two

Chapters one and two consider the principle of autonomy in regards to PGT. In chapter one I examine what the principle of autonomy entails and whether one is justified in exercising a right not to know genetic information about oneself in the name of autonomy (the right to remain in ignorance). An important distinction is drawn between autonomous choices generally and autonomous choices about how we shall conduct our lives. I consider two hypothetical cases and conclude that ignorance of genetic information cannot be justified in the name of autonomy and furthermore that where genetic information is pertinent to one's future autonomy, one cannot exercise a right not to know in the name of autonomy.

Chapter two considers whether testing children for diseases that will develop in adulthood may in fact promote and enable their developing autonomy. I argue that whilst testing at risk children does prevent the future adult being able to make a choice not to be tested, under certain circumstances the benefits to children's developing autonomy should be considered a compelling reason to test them. In other words, the benefits for autonomy's development in terms of enabling the child to begin to make plans and decisions about their own future in the knowledge of such information, trumps the child's possible future choice not to know.

The third chapter considers genetic discrimination in the area of life insurance from a New Zealand perspective, and begins by questioning whether discrimination on the basis of genetic makeup is invidious and unfair; should we resist genetic testing through fear of discrimination? Whilst there is evidence to suggest that individuals are fearful of genetic discrimination, and some believe that they have been unfairly discriminated against, to date no large-scale discrimination has been verified (either in New Zealand

or elsewhere). Consumer groups and the general public have also expressed concerns that genetic information could be misused by insurance companies. I also examine what genetic information is able to tell us about our future health and whether such knowledge differs significantly from other types of non-genetic medical information. I claim there are strong pragmatic reasons that have not been adequately addressed in the literature to think that life insurers will not adversely discriminate against large numbers of the population, thus such fears are not warranted and neither should we resist genetic testing in the life insurance context. Finally I consider an important objection to my discussion.

A central concern in the literature suggests testing children for adult onset diseases may result in a number of psychological harms. The fourth chapter focuses on some of these putative harms and whether they justify the current prohibitive policy. I examine the following psychological harms that are frequently raised in the medical and bioethical literature; ‘vulnerable child syndrome’, limited horizons and damage to the child’s self esteem. I conclude that these harms are unlikely to occur as a result of PGT and that in some cases, testing children may provide significant benefit to them.

Chapter five examines why it is considered important to tell at-risk children genetic information about hereditary conditions which will go on to impact their lives in a significant way, yet at the same time, refuse to genetically test them for the disease for which they are at-risk. In other words, if it is important to inform children that they are at-risk for a disease that exists within the family, why shouldn’t they also grow up knowing their actual risk for the disease (whether or not they carry the genetic mutation)? Central to my discussion is the importance of the process of disclosure and the environment in which genetic information is divulged. I conclude that PGT of

children for adult onset diseases in a supportive and caring environment may offer children different choices rather than fewer choices as informed adults and that in some families, testing may be seen as an extension of the disclosure process. Thus the reasons given to defend disclosure to children of genetic conditions within the family are also important reasons to defend PGT of children for adult onset diseases.

Finally I consider the conclusions made in both sections of the discussion and reflect on whether we ought to genetically test children for adult onset diseases or continue to support current policy. I consider the implications these positions may have not only for children themselves, but also the families and professionals involved in testing.

Chapter 1. The right to remain in ignorance about genetic information – can such a right be defended in the name of autonomy?

Within the field of medical ethics, in the last 20 years or so in New Zealand, there has been a growing awareness and respect for the patient's right to know information about themselves. As a result of the Cartwright Report in 1985, the Code of Rights for Health and Disability became law on 1 July, 1996³⁴. Patients are recognised as having a number of important rights, two of which are; the right to be fully informed and the right to effective communication³⁵. One's right to be fully informed includes being told the results of tests and procedures as well as an explanation of their condition and the treatment options available. Thus the right to know requires that individuals are given personal information – this enables them to make informed choices and to give their informed consent. John Harris claims: *“since autonomy is necessary in order that every individual can pursue freely and in their own way the things that for them make life valuable or meaningful, they have the strongest entitlement to whatever information about themselves will, in their own judgement, best help them to do this”* (Harris, 1989 p 209).

³⁴ The Health and Disability Commissioner Act. Available online. URL: <http://www.hdc.org.nz/page.php?page=theact>

³⁵ http://www.hdc.org.nz/act_code/the_right_of_code/clause2.html

If for the sake of argument we agree that individuals have a right to know - grounded in respect for their autonomy - perhaps individuals also have a right not to know that stems from respect for their autonomy? According to Wertz et al, "*autonomy includes both the right to know and the right not to know one's genetic status*" (Wertz et al., 1994 p 879). When we consider trivial examples – revealing the score of a sports game I want to watch later or the plot of a movie I hope to go and see – we assume that others will respect our wish not to be informed (of such information) when we ask them not to tell us. I am probably right to think that you should respect my desire not to know such information (out of minimal consideration, if nothing else) but am I correct in believing that my right not to know can be defended in the "*name of autonomy*" (Harris & Keywood, 2001 p 421)?

Certainly if we consider recent anti smoking advertisements in the media, it is clear that the State considers that we do not have a right to remain ignorant regarding certain information; namely the health effects of smoking on ourselves and others (passive smokers). Graphic illustrations of the consequences of smoking on our lungs, heart and blood vessels clearly aim to inform individuals about the harmful costs of smoking on our health. Presumably such advertising, aside from the financial costs to our health care system, is motivated by two features: harm to one's own health and the health of others.

The same could be said for drunk driving and speeding campaigns on television and in the print media. Behind such campaigns is the assumption that upsetting visual imagery and statistics will shock individuals into taking certain information on board and thereby change their behaviour.

In the cases above there are three important points to make clear:

First, where not knowing certain information is likely to lead to third parties' being harmed, it is clear that we may not have a right not to know, i.e. to remain in ignorance. Consider the two children who confront their mother because they are concerned about her health. They ask her to see a doctor because they are worried she is ill however, she refuses claiming she'd rather not know such information. They respond that her not knowing if she is sick may harm them as she is their only caregiver and if she is ill their future well being may be at stake. Ignorance is not a defence when others may be harmed by our actions (or inactions).

Second, individuals may not have a right to remain in ignorance where not knowing certain information is likely to lead to their being harmed. An important function of any society is to educate and enable its citizens to be able to live their own lives as they so determine. Respecting self determination requires that individuals have access to information so that they can make informed decisions. To that end our healthcare system is obliged to provide an extensive range of healthcare services to its citizens. Presumably what underlie television campaigns of the kind described above are concerns about how ignorance may harm individuals. For instance, the individual who is unaware that drinking alcohol and driving is a dangerous practice, or those who do not know about the adverse health effects of smoking. Informing individuals about the consequences of certain actions provides them with information they can use to make decisions in reasonable knowledge.

Third, the examples above also imply a more challenging and contentious position; that individuals cannot demand a right not to know in the name of autonomy. When we

consider what the demanding philosophical theory of autonomy entails, one may claim that ignorance of important information is inimical to autonomy. Moreover, ignorance may go on to thwart our future autonomous choices. Thus it may be *prima facie* that where ignorance is likely to frustrate out future autonomous goals, we cannot have a right not to know which is grounded in autonomy.

In this chapter I explore the notion of a right not to know. Throughout the discussion I will talk both of a *right not to know* and a *right to remain in ignorance*. I use both terms interchangeably. Leaving aside the claim that individuals may not have a right not to know where not knowing may lead to others being harmed, I will focus on one's putative right not to know genetic information about oneself where such a right is defended in the name of autonomy. Specifically I will examine whether it is consistent both to claim that one has a right to know grounded in one's autonomy whilst also claiming that one has a right to remain in ignorance, grounded in one's autonomy.

In the context of this discussion, my right not to know simply means I am morally permitted to exercise my right and everyone else has a duty to let me not know; that is, they have a duty not to interfere with my ignorance. Does autonomy justify my exercising a right not to know important genetic information that is pertinent to many future choices I may make? To answer this question, it is necessary to give a brief account of personal autonomy and what I claim it entails of us as moral agents.

Autonomy

Although the notion of autonomy is understood in a variety of different ways (Arpaly, 2003 p 118), and criticized accordingly (Gaylin & Jennings, 2003), it is commonly held that autonomy "*is a feature of persons and it is a desirable quality to have*" (Dworkin, 1988 p 6). Deriving from the Greek terms: *autos* (self) and *nomos* (rule or law), the

autonomous person is essentially one who is free to determine their own life – that is, the individual is able to choose from a variety of different options without interference or coercion from others.

In the liberal philosophical tradition, autonomy assumes an elevated role because it is central to how we understand ourselves and the world around us. *“The way we perceive of ourselves as distinct from inanimate objects, the way in which we interact with our surroundings, and the way in which we understand the causes and responsibility for the events which take place around us are wrapped up in our conception of autonomy”* (May, 1998 p 13).

Kant is perhaps the most influential philosopher linked with the notion of personal autonomy. He argued that it was the ability to reason that gave human beings their intrinsic value and set them apart from all other beings (Gregor, 1996 p 146). The capacity to make rational decisions and guide one’s own life accordingly sits at the heart of Kant’s idea of autonomy. An important consequence of his position is that an autonomous agent is themselves an end, and can never be used solely as a means to the ends of others.

For Mill, personal autonomy was connected with personal liberty; as far as possible individuals should be free to live their lives as they so desire, as long as their actions did not harm others. Thus Mill was explicit that society was not to interfere in the self regarding actions of others: *“Over one’s self, and over their own body and mind, the individual is sovereign”* (Mill, 1974 p 69). In order to live as one rationally chooses, Mill argued, it is important that the individual receive an education that exercised the various faculties; *“he who chooses his plan for himself employs all his faculties. He must use observation to see, reasoning and judgment to foresee, activity to gather*

materials for decisions, discrimination to decide and when he has decided, firmness and self control to hold to his deliberate decision” (Ibid., p 123).

What motivates both accounts of autonomy, in fact what is central to autonomy in philosophical literature generally, is that individuals exercise their capacity to reason in determining how they shall live. If individuals are to build the kinds of lives they desire, they must have access to information that concerns them. This is why the right to know is so important.

According to Haworth, personal autonomy demands critical reflection; namely having the ability to reflect critically on one’s needs, wants and situation (Haworth, 1986 p 54). Seen in this way, autonomy is extremely demanding because it requires thoughtful and considered deliberation. It entails assessing the consequences of acting in particular ways, considering the impact our actions may have for others, and taking responsibility and being accountable for the decisions we make. Seeing autonomy in this way involves our making particular deliberative choices. It requires that we pursue information and knowledge so that the choices we make are informed – that they truly reflect what we want for ourselves (and those we care about). Thus, when we speak of autonomy, we are speaking of a reasoned, deliberate way of living.

Autonomy understood in this way refers to an extended process through time. It is important to be clear about the distinction made here, for one may make autonomous choices, but live a life that is not autonomously chosen. Those individuals incarcerated in prison may make many autonomous choices day to day, but they do not govern their own lives, thus they are not autonomous in the wider sense that I distinguish as important. One may make autonomous choices such as deciding what to wear or when

and what to eat, yet be unable to make autonomous choices about how to conduct one's life. It is the latter understanding of autonomy that is crucial to this discussion.

It is also important that my choices are freely made. We value being able to make choices because in deciding what to do (or not to do), we exercise our decision-making capabilities which in turn reflect what we want for ourselves. That is, we decide amongst an array of different options what we intend for ourselves (and others), with *"understanding and without controlling influences that determine our action"* (Beauchamp & Childress, 1994 p 123).

The right not to know

Having discussed a philosophical conception of autonomy and what it requires of us, let us consider whether one can autonomously decide to remain in ignorance about one's genetic constitution. Consider the following hypothetical cases:

Sandra's mother Lily died of breast cancer at the age of 31 when Sandra was 10 years old. Lily's sister and several aunts also died of the disease. There is also a history of ovarian cancer. Sandra has grown up knowing that she is at risk for both breast and ovarian cancer. Her GP has recommended to her that she should consider susceptibility testing because it is known that a close family member carries a germ-line mutation at BRCA1. If Sandra carries the mutation, she has a greater chance of developing breast and ovarian cancer and is more likely to develop the disease younger than someone without the mutation. She refuses susceptibility testing claiming that as an autonomous adult she has a right not to know whether or not she carries the genetic mutation.

After months of deteriorating health, Tom's father is diagnosed with Huntington's disease (HD). Tom and his brother are told they have a 50% risk of carrying the genetic mutation for the disease. Tom refuses to be tested for HD. He claims that as there is nothing that can medically benefit him now if he tests positive for the disease, he'd rather not know. Furthermore, having weighed up the available options, it is his informed view to prefer remaining in ignorance: he, like Sandra, believes that he has a right not to know.

Can respect for autonomy justify their exercising a right to remain in ignorance? One can empathize with both Sandra and Tom's situation. Having both lost parents to a disease that is clearly manifest within their families, it is easy to understand their desire - perhaps in an attempt not to have to confront the reality of the disease - not to know. And we may well agree that no-one has the right to force them to know. But assuming that such claims were not made *'in the heat of the moment'*, and they had sufficient time to reflect on the ramifications of their situation, can their exercising a moral right not to know genetic information about themselves be defended in the name of autonomy?

Tom argues that he has weighed up the options available to him which suggests that he is reasonably informed about the disease's progression. Perhaps he has spoken to various specialists about the likely course of the disease, or has read literature within the area and feels that given existing knowledge in the area of HD, he would prefer to maintain his current lifestyle whilst remaining hopeful of a cure in the future. He may claim that exercising his right not to know is consistent with his autonomy because his choice not to know is informed: he knows all there is to know about HD. He argues that because he knows enough about the disease, he doesn't want to know any more (for instance, what it will mean if he is found to carry the faulty gene). He may reason that

such an act is consistent with respect for his autonomy because it is his autonomously informed and considered choice.

Tom claims that he knows enough about the disease to make an informed choice not to want to know if he carries the HD gene, yet what Tom does not know about HD is the all important (with regard to his future) fact of whether or not he carries the gene for it. And because it is his own future relation to HD he is refusing to know, he is giving up his autonomy, not exercising it. Therefore it seems incompatible for Tom to claim that not knowing certain genetic information is consistent with him exercising his autonomy. This is for two reasons:

First, remaining ignorant about whether he carries the HD gene means that he cannot make informed decisions about his future because he does not have significant information to hand.

Second and related to the first reason is that his choice not to know may frustrate his future autonomous goals: he may go on to make choices that are self-defeating. For instance, if Tom wrongly assumes he carries the HD gene, then he may decide to forego having children of his own in the mistaken belief that they too would be at risk for the disease. He cannot exercise a right to ignorance in the name of autonomy because some of the important decisions he goes on to make in uncertainty (ignorance) may thwart his future life goals.

As I discussed earlier, making autonomous choices involves being cognizant of the consequences of one's decisions. It entails weighing up the various options available however difficult and distressing they may be. It also involves being honest with oneself about what the choices will mean for the future which means recognizing when one's choices are being unduly influenced by fear or guilt for example.

Sandra's decision not to be tested may be influenced in part by trepidation of what she remembered her mother enduring. She may rationalize ignorance of her risk as a way of postponing having to confront her own fears about death and dying. Or she may feel that only she truly knows her mental strengths and weaknesses and at this point in time ignorance is bliss. Such rationalizations are understandable, but we should not be tempted into assuming that remaining ignorant is consistent with autonomy.

Part of deciding how to live our lives is taking responsibility for ourselves and the choices we have to make, which means confronting what the future may hold for us even when we would rather not know it. I undercut my own autonomy if I reject knowledge pertinent to my future choices and life because autonomy involves shaping my own life with knowledge, but I do not undercut it if I reject knowledge which is not pertinent to any choice I could possibly make in the future.

When Tom says that he does not wish to know whether he carries the Huntington's gene and Sandra says that she does not want to undergo susceptibility testing for breast cancer, we ought to be sensitive to their position. Although sensitivity does not imply that we should agree with their position, their putative right not to know may be defended for example, by a consequentialist argument. Having weighed up the benefits and harms of remaining ignorant, the result may be that more benefits will ensue overall in not knowing certain information. For instance, Tom may claim that not knowing and remaining hopeful benefits him far more greatly than knowing for certain (even allowing for the fact that he may not be at risk for the disease at all). This is because he knows better than anyone his psychological strengths and weaknesses in coping with

such knowledge. He may reason that were he to be tested and found to carry the gene, such an unbearable burden would lead him to consider suicide³⁶.

We are the architects of our lives and require knowledge if we are to build the kinds of lives we want to live, thus it appears contrary to autonomy to claim that one has a right to know genetic information whilst at the same time defending a right not to know genetic information. We can understand and sympathize with the individual who claims a right not to know – perhaps they would be willing to sacrifice autonomy in preference to knowing one may face death prematurely – but such an individual cannot justify such a right in the name of autonomy.

Conclusion

In this discussion I have examined the claim that one can exercise a right to remain ignorant on the grounds that it is consistent with one's autonomy. In the hypothetical cases presented I focused on whether an individual has a right to remain in ignorance when the information concerned is their genetic knowledge.

I began by considering what the notion of autonomy entails. When autonomy as self determination is understood as involving critical self reflection, deliberation and thoughtful and competent decision making, it becomes clear that in order to be autonomous one must have information at one's disposal to be autonomous. We are responsible for our own lives and as such have an obligation to be informed. Such a conception justifies our right to know. When information is denied to us, unavailable or too complex to understand, we cannot make autonomous choices because we are

³⁶ Within the medical and bioethical literature, concerns have been raised that predictive genetic testing may lead to an escalation in deaths by suicide among those who carry the Huntington's gene. However review research has shown that "*few adverse events have been described and no obvious contraindications for testing people at risk have been identified*" (Meiser & Dunn, 2000). See also: (Almqvist, Bloch, Brinkman, Craufurd, & Hayden, 1999) and (Broadstock, Michie, & Marteau, 2000).

ignorant about the options available to us. We are not responsible for our lives when we cannot make informed choices.

The individual who claims a right not to know on the ground that exercising such a right is compatible with one's autonomy is mistaken. Their motives may be understandable, indeed we may find their reasons clear and compelling, but autonomy does not and cannot tolerate remaining ignorant when central to being autonomous is making informed choices with as much knowledge as is available to us.

Thus we cannot defend a right not to know our genetic information in the name of autonomy alone. It may well be that the right not to know can be successfully defended on consequentialist grounds, the justification being that the benefits of not knowing genetic information outweighs the burdens of knowing. Autonomy however, demands that we exercise our capacity to reason and this surely entails the pursuit of pertinent genetic information not the rejection of it.

Chapter 2. Predictive genetic testing of children and respect for autonomy.

Introduction

Predictive genetic testing of asymptomatic children for diseases that will not develop until adulthood and for which no cure or medical benefit is available is not recommended by international genetic service providers and professional genetic societies (CEJA, 1995), (Human Genetics Society of Australasia, 2003), (Clarke et al., 1994), (World Health Organisation, 1997), (Huntington's Disease Society of America, 1994), (National Advisory on Health and Disability, 2003), (American Academy of Pediatrics, 2001), (National Society of Genetic Counselors, 2003). As noted earlier, this is for a number of important reasons, one of which is that children have a right to autonomy, and *“testing in childhood removes the possibility of that individual making an autonomous decision as an adult”* (Human Genetics Society of Australasia, 2003). These concerns are also reflected in the report of a working party of the Clinical Genetics Society (UK) which claims that such testing of children should not generally be undertaken: *“We would generally advise against such testing, unless there are clear cut and unusual arguments in favour. Formal genetic testing should generally wait until the “children” request such tests for themselves, as autonomous adults. This respect for autonomy and confidentiality would entail the deferral of testing until the individual is either adult, or is able to appreciate not only the genetic facts of the matter but also the emotional and social consequences of the various possible test results”* (Clarke et al.,

1994). This conclusion is also reached within much of the medical and bioethical literature (Bloch & Hayden, 1990), (Clarke & Flinter, 1996), (Wright Clayton, 1997), (Michie & Marteau, 1996).

It is important to examine this prohibitive stance and the grounds given to defend it, for a number of reasons: *“As genes for more common illnesses are identified, physicians will be under increased pressure from families to test children and adolescents for various disorders and predispositions”* (Fanos, 1997 p 22). As the tests to accurately predict an individual's disease risk become more reliable and cheaper to administer, it is possible parents will request them for their at-risk children. There is also a concern that such tests may one day be available over the counter (Burnside, 1997). Many biotechnology companies already advertise genetic testing services (for tracing paternity and ancestry) over the internet³⁷. Some companies offer testing for genetic diseases such as BRCA1 and BRCA2³⁸. At the present time PGT of adults is preceded by extensive counselling and support. Were such testing to become available parents may organise to have their children tested without either party being fully aware of the ramifications of what the test results may mean.

We should note that such guidelines do not clarify what respecting the future autonomy of children involves, but simply assume that predictive genetic testing will breach it.

Whilst I agree that respecting the future (developing) autonomy of children is imperative, we should not assume that a prohibition on testing will so obviously

³⁷ Biotechnology companies, Genelex, Dnanow, Gtldna, Genetree, Dna Security, Inc and Dna Testing Centre, Inc all offer paternity and ancestry testing via kits available for sale on the internet.

Genelex; <http://www.genelex.com/>

Dnanow; <http://www.genescience.com.au/dnanow/birdbotframe.htm>

Gtldna; <http://www.gtldna.com/>

Genetree; <http://www.genetree.com/>

Dna Security, Inc; <http://www.dnasi.com/familystudies/>

Dna Testing Centre, Inc; <http://www.dnatestingcentre.com/>

³⁸ Myriad; http://www.myriadtests.com/provider/benefits_brac.htm

preserve their future autonomy by offering them more choices. Not testing at-risk children for adult onset diseases may in fact limit options available to them, namely of having known the test result since childhood (Michie, 1996) and successfully incorporating that knowledge into one's self identity "*during their formative years*" (Robertson & Savulescu, 2001 p 39).

In this discussion I consider whether PGT for adult onset diseases may in fact promote and facilitate their developing autonomy. That is, testing may provide clear and defined benefits to the child.

Discussion

Respect for autonomy is a cornerstone of contemporary bioethics (Beauchamp & Childress, 1994). The ways in which we respect the autonomous choices of others says much about how we value them as individuals and the importance we attach to their lives and our own. As a value (in medical ethics) autonomy, "*is often held to be more important even than the curing of an illness when we allow persons the right to refuse treatment*" (May, 1998 p 16). Seeking informed consent, respecting the choices of others and maintaining patient confidentiality are all ways in which we respect the autonomy of others and the autonomous choices that they make. We also value raising children to become autonomous, self confident, responsible citizens. As I noted in chapter three of the first section, we consider it a central parental obligation to facilitate children's developing autonomous decision-making capabilities. Such respect shows how important the concept of autonomy is in determining how we should act towards those in the moral community.

Central to my understanding of autonomy, and the way in which I intend it to be understood in the context of this discussion is an emphasis on the autonomous choices

an individual makes rather than the individuals themselves. I may be said to be an autonomous person because I am a mentally competent adult, live my own life according to my dictates, exercise reason and deliberate about the range of options available to me, however I am not making an autonomous choice when I pursue a course of action without understanding or taking into consideration the relevant implications of my choices. For instance, as an autonomous person, I do not make an autonomous choice about my future when, in a drunken moment, I decide to insult my employer.

In perhaps a more contentious example, I may be qualified to act autonomously when I consent to major surgery; however I do not exercise my autonomous choice when, out of fear, I choose to ignore the surgeon's advice to read the consent form. I may have consented to surgery, but my consent is not given autonomously, and thus it is no consent at all. Understood in this way, making an autonomous choice is demanding. It requires that not only do individuals have access to information (as noted in the previous chapter), but that they reflect on their course of action clearly taking into account the consequences and implications that may result. Ignoring or refusing to heed important information, especially about one's health may go on to compromise or even forfeit one's ability to make autonomous choices later.

Children, especially young children, are often said to lack autonomy, or rather lack the ability to make informed decisions about how to govern their lives. They generally cannot anticipate the consequences that may arise from their actions and are unable to think long-term about their own futures and the impact decisions made now may have on them. Parents are normally those entrusted with the authority to make decisions for their children; decisions that are to be made in the best interests of the child. However it

would be misleading to assume that children, even very young children, cannot make any autonomous choices in their lives. Given information relevant to their age and understanding children can make reasonable decisions for themselves. For instance, what they would like to wear, what they will eat for dinner or who to play with after school.

As parents, we encourage our children to begin to make choices in this way because encouraging them facilitates the development of their autonomy by enabling them in their decision-making abilities. Children *“do not emerge from a cocoon at age 18 with full blown decision-making capacity; rather their abilities to make good choices must be developed over time, a process that requires patience”* (Wright Clayton, 1997 p 244). Such a process facilitates the child learning to take responsibility for their actions, nurtures their self-confidence and determination, encourages them to consider how the consequences of their actions will impact upon others and educates them about the choices they will need to make as they prepare to direct their own lives. This necessitates providing children with information and knowledge. Generally however young children are unable to make autonomous choices when faced with complicated and often conflicting choices, especially in the area of health when the range of options available is often neither straightforward nor obvious. As young children need to be protected from their own actions as well as those of others, it is important to consider what can and can not be done to children because in the context of PGT, young children cannot give an informed view on whether they should be tested for an adult onset disorder (Wright Clayton, 1997).

Adolescents are a different matter. When they request testing because they are aware of a disease risk in the family, are concerned for their futures and want to know more

about the disease, they ought to be encouraged to discuss their concerns with family members and genetic counsellors (Clarke et al., 1994). Such questioning and deliberation clearly indicates an exercising of their autonomous capacities. The fourteen year old who knows a disorder exists within the family, who seeks information and requests that she be tested is exercising her developing autonomy and so her decision should be taken seriously and not be rejected simply because she is still legally considered a child. If we are sincere about respecting the developing autonomy of children as I believe we are, then a child's autonomous choices ought to be listened to in so far as they are accorded the same respect shown to an adult's autonomous decision. Furthermore we ought to seek their assent when making decisions on their behalf. However, having noted these points I will limit my discussion in this chapter to the more contentious circumstance of testing young children when they have not requested it for themselves. A request for testing therefore comes from the child's parents or caregivers³⁹.

The issue

The following hypothetical example makes clear the central issues that dominate this discussion:

Jon and Sue have 2 young children, aged 5 and 8 years old. Jon's father was diagnosed with Huntington's disease - a neurodegenerative disorder characterised by personality change and cognitive decline (Myers, 2004) - three years ago. Jon knows that he has a 50% chance of carrying the Huntington's gene and that his children are also at risk. After deliberating, he decides to be tested and the results show him to be positive for the disease; hence his two

³⁹ I will not address the case where prospective adoptive parents request that a child is tested prior to (and is a condition of) adoption. Testing would not be performed in this situation (Bloch and Hayden, 1990 p 2-3).

children have a 50% risk of carrying the Huntington's gene. Following a period of adjustment and discussion both parents request that their children be tested. This is for several reasons: Jon and Sue's primary intention is that testing the children will give them all information which will help shape the children's lives in an empowering, pragmatic way. If they test positive they will grow up understanding the disease and the part it will play in their lives, if they test negative they will grow up knowing it will not affect them in the way it will their father and grandfather. Regardless of the test outcome, both parents feel the children should grow up knowing what the future will hold for them from an early age and be able to make plans that incorporate a realistic future. Jon claims he wishes he had *always known* so that he grew up understanding the disease and had more time to prepare for his own future. Both parents claim that they have raised their children in an environment in which honesty and openness are central. They state that the disease is only one part of their lives. As the risk to the children is 50%, there is just as much likelihood that they will be free of the Huntington gene. Furthermore Sue argues, were the children adopted, they would have been told of their adoption from a young age. Jon asks, 'What harms may result if the children are not tested? When they are older will they accuse us of secrecy because we did not have them tested earlier? Doesn't not having the children tested imply that the disease is shameful and ought to be kept hidden?'

Should such a request be granted?

Clearly at the ages of 5 and 8 years, the two children are unable to make an informed decision about testing of this kind so it is important to look at the two claims being presented with respect to testing:

First, it is claimed that testing will benefit the children's developing autonomy because they will grow up in a supportive, caring environment knowing specific information that will help shape their futures in a realistic way.

The second claim states that openness and honesty are central to how the family live. It is implied that openness in the area of genetic testing will facilitate the children's developing autonomy. Sue comments that had the children been adopted they would have been told such information. It is also hinted that not testing the children implies certain information should be kept a secret, and thus is shameful.

Claiming that testing will benefit the children's developing autonomy by giving them important information appears reasonable. Part of understanding our place in the family and the world is learning about who we are, how we are connected to others and where we came from (our 'roots'). One consequence of this understanding is learning how to make decisions and take responsibility for our actions and ultimately our lives. We can only make informed decisions about what we want for ourselves and others where we have access to information and can make choices. Thus we prepare children for life by educating them in certain ways, exposing them to a variety of experiences that help shape their futures and guide their social and moral development. We do not bring children up in a social, moral or religious vacuum until they are old enough to decide for themselves how to live: hence we do not say to children; *'Just in case you don't want to know about Christianity, Islam or Buddhism when you are an adult, we won't tell you about them now'*. As children begin to develop their own identities they will

need to incorporate information into their lives that will shape and influence how they see themselves and others. Part of nurturing a child's developing independence and capacity for autonomous choice is allowing them the opportunities to make choices and helping them to accept the consequences of their actions. This marks the beginning of them becoming competent and developing an ability to reflect critically on what they need and want (Haworth, 1986).

If children are tested young and are found to carry a genetic mutation (for a disease that is present in their family), such knowledge becomes part of who they are and who they will become. Learning that one has a disease which probably will not manifest itself until one is much older may give the child time to become accustomed to such information and to grow up without fear of the disorder. Such knowledge may benefit the child as they *“may view the disease state as being normal and may even develop positive attitudes of identification with the affected family member”* (ASHG/ACMG et al., 1995). The child who is tested and found not to be at risk grows up knowing that whilst the disease resides within the family, she will not develop it. Thus her future plans and goals will be made in such knowledge. *“A fundamentally important fact about ourselves is how long we will live and how robust our health will be. To take the extreme case, it might make a great difference to our actions, if we learnt we were to live one more day or 40 more years”* (Robertson & Savulescu, 2001 p 42).

Sue links the disclosure of information about adoption to that of information derived from PGT. Were the children adopted, she argues, they would have grown up from a young age knowing such information. She implies that as the children are at risk for Huntington's disease they ought to be tested so that they grow up knowing such information in the same way that children are generally told that they are adopted.

Telling adopted children the truth about where they came from is important for their developing self identity during their formative years. Such disclosure respects the “*need of the offspring to know their ‘roots’*” (Basu, 2004 p 136). When individuals find out that they were adopted as adults many find it a “*crisis of the whole person - mind, body and soul*” (Schooler & Norris, 2002 p 50). They may also feel a sense of betrayal and anguish over the “*past mismanagement of the most intimate detail of one's life - one's personal identity*” (*Ibid.*, p 53). Where adoption information is withheld from a child, the result may be the “*erosion of the child's trust, loyalty and attachment to the adoptive family*” (Keefer & Schooler, 2000 p 4). Children who are told the truth about their adoption grow up knowing that being adopted is neither shameful nor should it be a secret that stays hidden. Relationships between parents and their adoptive children fare better when there is open and reliable communication (Hunter, Salter-Ling, & Glover, 2000), (Snowden & Snowden, 1997).

Is knowledge that one is adopted similar to knowledge that one has a disease which may not manifest itself until one is older? One response is to claim that knowledge of adoption is knowledge of a past event, whereas knowing that one has a genetic disorder that will not develop until one is much older is an event that is yet to occur.

Yet both kinds of information, disclosed at a young age, may assist in the development of a child's identity and self determination by presenting them with information that is crucial to how they will go on to live their lives. Growing up in the knowledge that one was adopted respects the child's development towards autonomy because it recognises the importance of children knowing their biological heritage - their place in the family and the world - and the significance this information has for the child as she matures.

Recently the importance of knowing one's genetic heritage was clearly expressed in the discussion surrounding reversing the anonymity of men and women who donate germinal material in IVF treatments (in the UK). In 1984 an inquiry led by Baroness Warnock enshrined anonymity for donors of sperm. Today she requests a reversal of that position. Warnock and others⁴⁰ now believe it is essential that children conceived in this way have access to information about their biological parents, including genetic details which could be crucial to their health. Children conceived through the use of donated sperm have a right to know the same information as those conceived naturally. *"It's absolutely deplorable for a child not to know what other children know"* (BBC, 2002). In January 2004, after widespread public consultation, the UK government announced that individuals who donate germinal material are to lose their right to anonymity.

If it is important that children are told of their adoption or their biological origins because such disclosure is important in the formation of their self identity and developing autonomy, can the same be said for testing currently healthy children for adult onset diseases? It may help to clarify this question by giving more attention to the adoption issue.

Suppose that a child had been adopted out to others to raise because her mentally ill mother's pregnancy had been the result of rape. Neither the mother nor her immediate family had been able, because of the brutal and ongoing circumstances, to raise the child. Would the adoptive parents think it beneficial to tell the young child the details surrounding her conception? I doubt they would. Telling a young child that her existence began in such a violent way may harm her because she may grow up feeling a

⁴⁰ Dr Mohammed Taranissi, Director of the Assisted Reproduction and Gynaecology Centre in London. Laura Spoelstra, Chairman of the National Gamete Donation Trust. Suzi Leather, Chairman of the HFEA. Marilyn Crawshaw, a spokeswoman for UK DonorLink.

sense of worthlessness and anger that the circumstances surrounding her conception resulted in her biological mother being unable to raise her. Also at an early age, the details may be too complicated for a child to understand. For instance, if the child's birth mother was a sex worker, telling her about her adoption history means also telling her about human sexuality. So while it is still important to tell the child the truth that she was adopted (if say for instance, she began to question her appearance in relation to her other siblings, or questioned what it meant when her friend told her she was adopted), one may avoid telling her specific details until she is old enough to question and understand the implications and consequences of such information.

There is certain information that will not shape children's lives in an empowering manner. Whilst we educate children about being safe we do not tell them, in detail, the horror stories of children who have been abducted and murdered by family members and strangers; such information will only serve to frighten and harm them. It is not in their best interests to know such detail at this young stage in their lives. It is important though to assist children to develop their capacity for autonomous choice, thus we give them information that will promote their autonomous abilities. We tell children about how to keep safe, where to go if they are feeling frightened or are being bullied, and who to contact if they are concerned or worried about anything.

It is important to restate this point. Information that intimately concerns children and will go on to have a significant impact on their future lives must be conveyed to them in an age-appropriate way so that the child grows up with an understanding that supports her in her decision making as she matures and develops. In this way one could argue that a child could be raised knowing that she carried the gene responsible for a particular disease (where she had tested positive or negative) by conveying such

knowledge in a way that was appropriate to her understanding, without the need to tell her specific details at an early age.

As Robertson, Savulescu and Parfit point out, human beings are psychologically disposed to discount harms that occur in the distant future. The further away they are the less harmful they appear. Thus one may claim that the sooner children learn about such future harms, *“the less psychologically damaging it would be”* (Robertson & Savulescu, 2001 p 43).

Being honest and open with children about their adoption or their biological origins is but one example of how important it is to tell children information that is crucial to their lives. Within the paediatric oncology literature there is evidence that where children are told they have cancer relatively early in their treatment they are better able to cope than children who indirectly learn about their cancer later (Bearison, 1991), (Koocher, 1986), (Slavin, O'Malley, Koocher, & Foster, 1981). *“Learning the diagnosis at a later age was a much different experience. It appears to have been much more difficult to integrate the information. Many children felt betrayed and shocked and feared the possible consequences of cancer even when reassurance was provided”* (Bearison, 1991 p 45). Claflin and Barbarin found that parents who limited disclosure to their young children (about their cancer diagnosis) in order to protect them from *“emotional arousal”* failed. *“The lack of disclosure may communicate the unintended message that the disease is a morbid, frightening secret to be worried about and that it is so toxic and dangerous it cannot be discussed openly”* (Claflin & Barbarin, 1991 p 188).

Openness and honesty do not imply that children must be told every detail about their disorder, but rather that they grow up understanding what the future will hold for them

in a way they can make sense of. Thus as they mature and begin to make decisions for themselves they will do so in increasingly full knowledge of what the future may hold. This is part of what it means to be informed and to take charge of one's own life (Cohen, 1998). We cannot make autonomous choices about our lives when we do not have access to information that is pertinent to us, and as children develop their autonomous capabilities as they mature, they must have access to important information that will influence their choices. Testing children at risk for adult onset diseases gives the child important information and offers them “*different choices not fewer choices*” (Robertson & Savulescu, 2001 p 41).

Objections

There are several ways someone may object to the discussion just presented:

My argument has claimed that testing young at-risk children for certain untreatable and unpreventable diseases may in fact facilitate their developing autonomy. This presupposes a certain kind of family environment; one in which the interests of the child are of paramount importance, and where the development of their autonomy is recognised and promoted. Some parents however may *claim* to promote the child's developing autonomy but really they request testing to relieve their own uncertainty and anxiety or to assist them in the spacing of subsequent children.

In response, this criticism is not an objection to the truth of the claim that PGT would be justifiable in circumstances where the knowledge from a test would facilitate the child's developing autonomy, but rather to its applicability in practice. How could we be sure that parents will use the knowledge in such a way as to facilitate the child's developing autonomy? I do not advocate testing young children without parents first undertaking appropriate counselling and support in order to establish that the interests

of the child are (known to be) of primary importance. Hence those health professionals responsible for supporting the family prior to the child being considered for testing would determine the appropriateness of testing in each context. Such support would entail talking to both the parents and child to determine their understanding of what the disease means for them and the implications of such knowledge for their lives.

The strongest objection to testing children is the one stated by the many international guidelines: if we test young children before they are able to make an autonomous choice to be tested, we violate their future autonomous choice in deciding not to be tested. In other words, if we test them now they can never (in the future) make a choice not to know.

In reply, in fact parents make many decisions for their children now that will result in them being unable to decide not to know certain knowledge in the future. In New Zealand most children are regularly tested for their academic aptitude when they begin high school to determine what stream (class) they should be placed into. Generally schools and parents welcome such testing on the grounds that knowing a child's academic abilities facilitates the child's learning by placing them in a suitable learning academic environment. Surely one of the reasons why it is considered important to determine who the under and over achieving students may be is that we recognise that giving them extra curricular support and encouragement nurtures their abilities. Whilst we acknowledge that children who are tested will never be able to choose not to know certain knowledge about their academic abilities we recognise that testing promotes their learning and fosters their development as future autonomous individuals. The benefits to the child from being tested outweigh the harms they may face later as adults.

As I discussed earlier, in many western countries at least, it is considered appropriate to tell children before the age of 18 that they are adopted. Even though telling a child they are adopted prevents their being able to make an autonomous choice not to know later we consider that telling them such information trumps their right not to know because it is vital for their developing self identity and autonomy.

One may further object that testing children now for their academic abilities benefits the child now for we can implement strategies to help children who are being left behind by their peers (individual, personalised tuition, extra-curricular activities), whereas testing children for diseases which will not manifest until they are adults will not benefit them now because the progression of the disease cannot be halted and neither can it be treated or cured. Such an objection interprets benefits too narrowly. I have claimed in this chapter that in fact testing some children for adult onset diseases may benefit them now by imparting important information to them in an age-appropriate way that will assist them in maturing into individuals capable of autonomous choice.

Finally one may argue that even where testing may provide young children with knowledge that will promote their autonomous capacity to begin to make informed choices about the direction of their lives, there are more important issues to consider than future (violations of) autonomy. In other words, even if we are satisfied that testing young children for adult onset diseases will facilitate rather than foreclose their autonomy, it is still not clear that we are justified in testing them. It is important that we not overlook other possibly harmful consequences that may arise from PGT. These include future discrimination in insurance, health care, educational opportunities and employment, psychological harms such as depression, altered family dynamics,

‘survivor’ guilt and breaches of confidentiality. These are important considerations, some of which will be addressed in the following chapters.

Conclusion

The guidelines that recommend prohibiting PGT of children for adult onset diseases claim that testing violates the child's future capacity (as an adult) to make an autonomous decision not to know. I have argued that whilst testing at-risk children does prevent the adult (they will become) making a choice not to be tested, under certain circumstances, the benefits to children's developing autonomy should be considered a compelling reason to test them. In other words, the benefits for autonomy's development in terms of enabling the child to begin to make plans and decisions about their own future in the knowledge of such information, trumps the child's future decision not to know.

To say that telling children of their adoption violates their being able to make an autonomous decision not to know as an adult misses what is crucial about such information. Disclosing such information during a child's formative years when their self identity is being shaped, assists them in understanding and learning about their place in the world; who they are connected to, what such knowledge will mean for their future and the plans they intend to make knowing what they do about themselves. If we refrain from testing children who are at risk of developing adult onset disorders we may in fact be teaching them that ignorance is a good way of life (Cohen, 1998). Ignorance is surely the antithesis of autonomy.

When parents request that their young children be tested principally because they believe that testing will enable and promote the child's self identity and developing autonomy, I claim serious consideration must be given to such a request. It respects not

only the desire of the parent to do what they consider in the best interest of the child, but also the child as an entity whose capacity for autonomous choice is acknowledged as important.

Chapter 3. Genetic testing and life insurance: should we resist genetic testing through fear of invidious discrimination?

Introduction

One important reason for defending a prohibitive stance in relation to genetically testing children for adult onset diseases is that children who are tested before they are able to make their own informed decision (to be tested as an autonomous adult) may find it extremely difficult to secure various kinds of insurance as adults: they may face invidious discrimination as a result of their genetic makeup. The HGSA notes that *“children should be protected from discrimination on the basis of predictive testing results. This includes eligibility for insurance and employment”* (Human Genetics Society of Australasia, 2003). The concern about invidious genetic discrimination in the areas of employment and insurance is also raised by many genetic testing protocol guidelines (CEJA, 1995), (Canadian Paediatric Society, 2003), (ASHG/ACMG et al., 1995).

In this discussion invidious genetic discrimination refers to the unfair *“treatment of individuals or their relatives on the basis of actual or presumed genetic differences”* (S. D. Taylor et al., 2004 p 225). Insurance companies can discriminate against individuals where their actions are based on sound actuarial data. For instance, the individual who smokes may be offered insurance cover at a higher rate than a similarly placed

individual who does not. Such discrimination is not unfair because the costs of smoking are known and supported by sound evidence.

The concern that the information derived from genetic tests may be used to unfairly discriminate against individuals seeking various kinds of insurance is also raised within the medical, legal and bioethical literature (Launis, 2003), (Harper, 1993), (Natowicz, Alper, & Alper, 1992), (Billings et al., 1992), (Hubbard & Elijah, 1993), (National Health and Medical Research Council, 2000). Consumer groups, the general public and those with genetic conditions have also expressed these concerns specifically in the context of life insurance (Matloff et al., 2000), (Shinaman, Bain, & Shoulson, 2003), (Genewatch UK, 2001).

Whilst there is evidence to suggest that some individuals are fearful of genetic discrimination in relation to life insurance, and some believe that they have been unfairly discriminated against (Lapham, Kozma, & Weiss, 1996), (Hall & Rich, 2000), (Low, King, & Wilkie, 1998) to date no large-scale discrimination has been verified in New Zealand or elsewhere (Bonn, 2000), (S. D. Taylor et al., 2004), (Nowlan, 2002), (Armstrong et al., 2003), (Sankar, 2003). Several individual cases of genetic discrimination have been documented and verified in Australia and some inconsistencies in assessing genetic information have been reported in the UK in the life insurance context (Low et al., 1998). Many studies to date however, have relied *“predominantly on unverified and in many instances anonymous accounts of individuals’ subjective impressions of whether they received inequitable treatment from third parties such as employers or insurers”* (Otlowski, Taylor, & Barlow-Stewart, 2003 p 1).

I begin this chapter by briefly commenting on the life insurance industry and the importance of disclosing information and knowledge when applying for insurance cover. I refer to life insurance as it operates in New Zealand; however the discussion is relevant for many other countries where the life insurance industry is broadly similar. I then discuss what genetic testing is able to tell us about our future health and life expectancy and the implications this may have for us by addressing the question, 'Does genetic information differ relevantly from other kinds of non-genetic medical information?'

I claim there are strong pragmatic reasons that have not been adequately addressed in the literature to think that life insurers will not invidiously discriminate against individuals solely on the basis of their genetic makeup.

Finally I consider an important objection to my discussion. It is important to be clear about what genetic information can tell us about our health because the future of genetic medicine has important implications for us all. This is especially so for children in relation to whether testing them now for adult onset diseases will result in them being unfairly discriminated against as adults.

Much of the medical, bioethical and legal literature focuses primarily on the health insurance market, particularly as it relates to the American context, where many employers purchase health insurance in bulk for their employees. Whilst it is true that all insurance companies (and indeed many other third parties) may have an interest in the information obtained from genetic tests, life insurers potentially have a very strong incentive to (want to) use genetic information to rate applicants as individuals purchase their own cover and may take out very large policies (McEwen, McCarty, & Reilly, 1993). Advances in understanding genetic information purportedly seem to offer

insurers a much more accurate way of determining the risk of an individual's premature death or morbidity.

The life insurance industry

Insurance is grounded in two related and complementary principles: those of solidarity and equity (Harper, 1993). Solidarity involves the sharing by everyone of both benefits and costs, whilst equity implies that the amount individuals contribute ought to be roughly in accordance with their recognized level of risk (Lloyd et al., 1993), (Mittra & Sulston, 2004), (Harper, 1993).

In New Zealand⁴¹ life insurance has two primary roles; *“to enable people and businesses to manage the financial risks of individuals' deaths and to provide vehicles for saving and investments”* (New Zealand Law Commission, 2004 p 1). Generally however, a person only needs to consider life insurance if their death will adversely impact on another financially (that is, someone else is financially dependent on them).

Insurers are in the business of risk assessment and discrimination. Individuals seeking life insurance are categorised into groups on the basis of certain factors, some of which they have no control over, and life insurance companies set their premiums depending on the statistical likelihood that groups will go on to make claims on their insurance policies (Hubbard & Elijah, 1993 p 141). The measures insurers put in place to differentiate between people underlie the underwriting process.

⁴¹ Within New Zealand, the life insurance market is varied. Some companies are owned locally although the majority are managed and serviced by overseas companies. In March 2005, of the 41 life insurers offering policies in New Zealand, all but one had an Australian parent company (Ministry of Economic Development, 2005). A number of overseas owned banks offer life insurance policies (Westpac Life, BNZ Investments and Insurance, NBNZ Life Insurance and ANZ Life) in New Zealand (New Zealand Law Commission, 2004). When comparing four life insurance companies offering cover in NZ (Sovereign (ASB Group), AXA NZ (National Mutual), AIA New Zealand (American International Group, Inc.(AIG)), Asteron (Promina Group)), only AXA NZ specifically asked that any previous genetic test results be disclosed. The other three requested disclosure of any 'medical test' undertaken. Such terminology strongly implies the inclusion of genetic tests.

Currently in New Zealand, as in many other countries, life insurance companies cannot require that applicants take a genetic test as a condition of being offered cover, but if such tests have already been undertaken, the results must be made available to the company if they are requested (duty of disclosure). According to the Investment Savings and Insurance Association (ISI) policy on genetic testing, “*life insurance companies may request that existing genetic test results are made available for the purpose of clarifying a risk*”, but they “*cannot insist that applicants undergo genetic tests*” (Investment Savings and Insurance Association of NZ Inc, 2004). Insurers may request the results of a genetic test if they consider such information relevant to the decision to provide insurance and if so, whether to do so at standard rates (National Health and Medical Research Council, 2000).

Life insurers (indeed all insurers) require information from applicants in order to assess their risk (and hence their attractiveness or suitability to insure). Individuals who know they are at-risk of inheriting a genetic disease, or those who have been tested, must disclose this fact when applying for cover. This is because the relationship between the life insurance company and an applicant centres on trust. Both parties have to be confident that each will honour its commitment to honesty; central to such commitment is that relevant information is available to each participant.

When an individual knows relevant information about their health and does not disclose it to the insurance company, they may be offered a policy suited to someone with a lower risk. This situation is termed ‘adverse’ or ‘anti-selection’, and insurance companies are at pains to minimise the incidence of it. Insurers are potentially disadvantaged because they face higher risks of a large payout and policy holders risk paying considerably higher premiums.

It is of particular concern where an individual takes out very large cover, as was experienced by insurance companies in the United States in relation to HIV⁴² infection in the 1980's (Lloyd et al., 1993). The consequences may be costly if adverse selection is widespread: all policy holders face increased premiums, low risk holders may leave for competing companies, and insurers may have to pay out for expensive claims (Sorell, 2002). According to some commentators if insurance premiums become so elevated that not even the high risk take out insurance cover the market will eventually collapse (Radetzki, Radetzki, & Juth, 2003 p 40), (M. O'Neill, 2005), (Rothstein, 1998).

Failure to disclose relevant information about one's health or lifestyle activities may result in a contract being invalidated later (if the company finds out information was deliberately withheld), or cover being suspended until the relevant information is available to the company. More importantly, deliberately not disclosing a known risk to an insurer amounts to cheating not only the company but fellow policy holders. Quite simply, deliberately withholding relevant information (disclosure of such information underlies the basis of a contract), may unfairly advantage the policy holder and is deceptive and equivalent to theft.

Discussion

What is central to this debate is knowledge (or lack thereof) of risk specifically the knowledge of risk resulting from genetic testing. The individual who grows up in a family where there is no history or knowledge of family members inheriting diseases (perhaps because they are a very fortunate family, or do not discuss such information amongst themselves) cannot disclose a risk he or she is unaware of. They will not

⁴² It is important to note that AIDS is an infectious disease. Individuals cannot be tested for their risk of developing AIDS.

undergo genetic testing (or even contemplate it) if they do not perceive themselves to be at-risk.

The individual who grows up in family where several members are known to have inherited a genetic disease (or where family members have died as the result of inheriting a disease) cannot escape knowing that they too may be at risk for the same disease. And if they know they are at risk they must disclose this knowledge if they apply for life insurance, in the same way they must disclose an alcohol addiction or a penchant to involve oneself in risky pursuits such as skydiving or base jumping. It is also important to state that some individuals who know they are at-risk for a hereditary disease may be better off being tested because the test result may return negative (no genetic mutation was found). They were once at-risk and are now known not to be at-risk (for that particular disorder), thus they will benefit from genetic testing in terms of securing life insurance cover at standard or preferred rates. Previously they may have been unable to obtain life insurance cover.

But what of the individual who gets tested because they know they are at-risk for an inherited disorder, and the test result returns a positive diagnosis (a genetic mutation has been identified)? Will they face invidious discrimination by way of being denied cover, or be offered cover at greatly increased premiums? Before answering that question I want to briefly consider the kinds of information life insurers already require and ask whether it differs relevantly from the information resulting from a genetic test.

Does genetic information differ relevantly from other kinds of non-genetic medical information?

Genetic information is deeply personal yet it also reveals information about one's genetic relatives (Campbell & Ross, 2003b). So we are rightly concerned about how

such information is used, the way in which it is stored and who has access to it. But these concerns do not differ in kind from concerns about other types of personal information disclosed to insurance companies or other third parties.

It is in the interests of insurance companies to attract individuals of low risk and discourage those who present a higher risk. Obviously life insurance companies would prefer to sell their insurance policies to individuals who are unlikely to become ill and die prematurely. Managing risk then will entail knowing information about individuals: what risky activities they participate in, family histories of disease, lifestyle choices, the influence of environmental factors, employment status and other factors that may impact on an individual's life expectancy and health outcomes.

Various kinds of non-genetic testing techniques reveal highly accurate and predictive genetic information about an individual and her family. For instance, ultrasonography can accurately determine that an individual has cysts on the kidney, liver and spleen, leading to the diagnosis that he or she almost certainly has polycystic kidney disease. Other non-genetic forms of clinical testing, for instance, blood pressure measurement, studying familial patterns of disease (family pedigrees), chloride tests on perspiration to test for cystic fibrosis, and cholesterol tests can also be highly predictive of genetically based disease. For that reason, genetic knowledge ought to be dealt with in the same way as other personal information and treated accordingly. It is puzzling that genetic information faces restrictions such as those enforced by legislation (or voluntarily imposed limits) when other forms of medical information can be and is used in the underwriting process to determine who is offered life insurance and on what terms.

Insurers already discriminate against individuals on the basis of their perceived risk; individuals who smoke pay higher premiums than their non-smoking counterparts

because the risks to one's health and life expectancy from smoking are costly and known. Individuals who participate in hazardous occupations or risky pursuits such as base jumping, parachuting, hang-gliding, motor racing and aviation (other than as a passenger) may face paying higher premiums in securing life cover. Discrimination of this kind is generally tolerated - although not always welcomed by those who pay higher premiums - because it is recognised that some individuals voluntarily partake in risky lifestyle choices that statistically place them in a higher risk category.

Individuals who knowingly participate in risky pursuits ought to personally carry the financial consequences of such risks. And in fact they already do. If you are a smoker, your premiums for life insurance will be significantly higher than a non-smoker. In New Zealand, a thirty nine year old woman smoker applying for cover will pay almost double the monthly premiums of a thirty nine year old non-smoker⁴³. Central to this point is the recognition that individuals who participate in risky or hazardous pursuits actively do something that contributes to them being 'high risk'⁴⁴. They are responsible for the risks they bear and therefore discrimination on the basis of their perceived risk is neither unfair nor invidious. *"After all, why should someone who smokes heavily and overeats in the face of repeated health warnings, and who will probably have contributed by his actions to heart and lung disease if he develops either, be treated the same as someone who, for health reasons, has given up cigarettes and kept their weight down?"* (Sorell, 2002 p 400).

⁴³ This was accurate for Sovereign, Asteron, Axa and AIA

⁴⁴ O'Neill (2005) raises an interesting point in relation to the notion of voluntariness and smoking. Many smokers are addicted to the habit and may have started smoking with an inadequate understanding as to the health risks. Undoubtedly many smokers would choose to give up the habit if, *"they were genuinely capable of following such a course of action"* (p 9). T Lemmens (2000) comments on the assumption that individuals are in control of certain behavioral traits. He notes that some preliminary research suggests that genetic factors may account, at least partially, for many behavioral traits and psychiatric disorders (See pp 375-376). This implies that individuals may not be responsible for the health consequences of certain conditions such as alcoholism and nicotine addiction. I will not address this here as it will take me too far from my discussion however it is an interesting point that requires further discussion.

Well what then of the individual who does not voluntarily participate in risky choices yet is categorised as high risk through no fault or choice of his own? The person who is genetically tested and knows they carry the mutation for HD has not done anything to contribute to his risk. He has not consented to the risk and probably, if given the choice, would prefer not to carry it. One could claim that the person who has to pay much higher premiums or who is refused insurance cover “*because of a genetically based risk, is penalised for a condition he cannot help*” (*Ibid.*, p 401).

Let me return to the question I raised earlier: will individuals who return a positive test result face invidious discrimination by way of being denied cover, or being offered cover at greatly increased premiums? Discrimination of this kind appears, *prima facie* invidious and unfair because we ought not to penalise individuals for circumstances that are beyond their control and for which no fault or blame can be attributed to them: in the same way that disability should not be reason for discrimination (MacDonald & Williams-Jones, 2002).

But in fact we do discriminate against individuals for circumstances that are beyond their control, and it is not clear that we are always unjustified in doing so. Men are disadvantaged when seeking life insurance cover because their life expectancy is shorter than women, thus they pay higher premiums than women do. Men cannot help living shorter lives, just as women cannot be blamed, or praised for having longer life expectancies.

Moreover, as I noted earlier, insurance companies already discriminate on the basis of disclosed family medical histories without having recourse to genetic test results when it is clear that such histories often have a strong genetic heritage. As well as routine information such as age, gender, weight and height, individuals are queried about their

general health. This includes specific questions about familial diseases, mental health problems, assistance from a health professional for - among others things - asthma, liver disease, epilepsy, haemorrhoids, gout, cancer, varicose veins, diabetes, and kidney disease. Applicants need to state any deformity, previous history of high blood pressure, and any abnormality of sight, hearing or speech. Many companies also ask specific questions about one's HIV status⁴⁵. Clearly such information is taken into consideration when an individual applies for life insurance.

If you are HIV-positive⁴⁶ - say as the result of a contaminated blood transfusion - you still face paying a higher premium than someone who is not HIV-positive. The fact that it is not your fault that you were infected with the HIV virus is irrelevant to the insurance company however sympathetic they may be. What is relevant here is the risk such an individual presents to the company and not the reason why they are at risk.

All such information disclosed to an insurance company provides them with a way of assessing risk and calculating whether an applicant will be offered cover and what the terms of the cover will be. This is due to the fact that the offer must “*reflect how likely they believe it is that the applicant will make a claim in future and the likely timing of such a claim. That is, they must offer terms which reflect the cost of providing the insurance*” (Investment Savings and Insurance Association of NZ Inc, 2000 p 5). It is clear though that generally one is not responsible or ‘to blame’ for many of the disease categories that are considered important in assessing risk.

⁴⁵ <http://www.insurancelink.co.nz/lifeMaster.php>. These included the following life and health insurance companies: Sovereign, AXA New Zealand, AIA New Zealand, and Asteron

⁴⁶ It is interesting to note that as of March 2005, the Dutch Association of Insurers has advised its members to insure HIV-positive people who have responded well to treatment, do not have other medical complications and who have never used injection drugs. It is expected that those who qualify will face costs comparable to people who have diabetes or are obese
<http://www.medicalnewstoday.com/printerfriendlynews.php?newsid=21039>.

Our intuitions seem to pull both ways here, on the one hand we consider it unfair that individuals who may be at risk of premature death are penalised for genetic factors that are beyond their control, on the other, it is surely unfair to low-risk policy holders that insurance companies should ignore probable risk by allowing an individual cover at the same premium as someone not at risk. As Nowlan succinctly notes, *“is it more “fair” to require low-risk individuals to make what is in effect an involuntary and non-tax deductible donation to help fund death benefits of others at higher risk?”* (Nowlan, 2002 p 195).

We should not lose sight of our intuition that individuals should not be unfairly penalised for factors beyond their control. Individuals who are at high risk of developing a disease that will almost certainly result in their premature death (or disability) should be assisted in securing financial security for their families because a decent, moral society supports and enables those who are disadvantaged by circumstances beyond their control. *“We should not allow others to carry a greater burden because of their genetic makeup”* (Radetzki et al., 2003 p 123). Many of the adult onset diseases that can be accurately tested for do confer a heightened level of risk. If you test positive for these diseases, you know that you will develop the disease in the future unless you die of something else before hand.

One plausible suggestion is that life insurance companies could offer a limited amount of cover to those individuals who are known to carry genetic mutations for single, highly penetrant diseases. As diseases caused by these particular mutations account for approximately 3% of all disease (Casey, 1997): a figure which is expected to decrease over time as many parents choose to avoid the birth of children with such disorders⁴⁷, a

⁴⁷ Through PGD and IVF, selective abortion, and the decision of informed at-risk parents not to have children of their own.

proposal such as this is not unreasonably prohibitive. This suggestion is given further credence by the two related and complementary principles that underlie life insurance: those of solidarity and equity. That is, although individuals ought to contribute an amount roughly in accordance with their recognised level of risk, sharing the benefits and burdens of genetic inheritance means recognising that some of us were dealt an unfortunate hand. Enabling individuals, who are disadvantaged due to their genetic inheritance, to secure financial security for their dependents, is the morally appropriate thing to do when the costs to us (as fellow policy holders) are minimal.

Pragmatic reasons

In New Zealand there is no move at the present time, to require individuals wanting life insurance to undergo genetic testing (as a condition of being offered cover). This reflects recent British Insurers Association (BIA) policy to extend its voluntary moratorium on the use of most predictive genetic tests until 2011. I suggest that underlying this stance is a number of pragmatic reasons:

First, although it is ridiculous to suggest that insurers may demand all potential life insurance applicants undergo genetic testing as a condition of securing cover⁴⁸, if for the sake of arguments they were to, one point clearly stands out: a number of individuals would return very favourable genetic test results that would put them in a low risk category. Generally low risk individuals will be young with correspondingly lower incomes; they may decide to spend their money on different financial schemes, reduce their cover because their genetic makeup predisposes them towards low risk, demand a reduction on their premiums, or decide not to take out cover at all. Insurance companies would then be left with those of medium and high risk applicants. Certainly

⁴⁸ Genetically testing all potential life insurance applicants would be time consuming and financially prohibitive.

low risk policy holders would be justified in demanding policy reductions if life insurers were to initiate policies that discriminated against those considered an increased risk: if I am financially penalised, because I represent a higher risk to the company, then you ought to receive a financial benefit because your risk is low.

Second, it is recognised that by far the majority of genetic disorders are multifactorial in origin. These are “*thought to be due to a variety of gene mutations, perhaps acting together, or to a combination of genes and environmental factors*” (Casey, 1997 p 7).

Many factors both genetic and non-genetic contribute to one’s risk of developing a disease and “*clinical validity and utility of most genetic tests have not yet been tracked or fully understood*” (Rothenberg & Terry, 2002 p 197) which means insurers should be wary of attributing too much predictive value on genes alone. For instance, although genes are known to be a major influencing factor in Alzheimer’s disease a recent study strongly indicates that individuals who participate in regular physical activity may be protected against dementia and Alzheimer’s disease as they age (Rovio et al., 2005).

For most diseases, a genetic test will not clearly indicate one’s actual risk of developing the disease (Vineis, Schulte, & McMichael, 2001), (Holtzman & Marteau, 2000). Two genes, BRCA1 and BRCA2⁴⁹ illustrate this point clearly. They are known to be implicated in familial breast and ovarian cancer, yet some women who (are known to) carry the BRCA genes do not go on to develop breast or ovarian cancer, “*and not everyone who develops breast cancer has BRCA1 or BRCA2 abnormalities*” (Collins, Weiss, & Hudson, 2003 p 555). Only between 5-10 percent of breast cancer cases are inherited the rest occur sporadically in women without a family history of the disease (Mincey, 2003), (M. R. Taylor, 2001). In fact there is “*no 100 per cent guarantee, in many cases, that the having of the gene will lead to the disease*” (Cook, 1999 p 161).

⁴⁹ For BReast CAncer

It has been claimed that “*calling them the genes for breast cancer hopelessly confuses a correlation with a cause*” (*Ibid*). This strongly implies that identifying genes that carry mutations does not tell the whole story about who will go on to develop diseases and who will not.

Third, as noted earlier, the cost to insurance companies to genetically test all potential applicants would be time consuming and financially prohibitive. Insurance companies want to attract clients and would be loath to initiate costly testing requirements as a condition of being offered cover. Moreover they would have to bear the costs of demanding mandatory tests regardless of whether the applicant ever takes up a policy. Not only would this place financial burdens on insurers but the resulting negative publicity would surely be a major deterrent to those contemplating taking out life cover. As life insurance is not the only way individuals can assure financial security for their families and dependents, and companies are under constant pressure to increase their sales, they are far more likely to accept rather than reject those who are marginally at risk (Nowlan, 2002 p 196).

Finally, and related to the second point, all of us carry deleterious genes that theoretically put us at risk of disease. In the United States, the Director of the National Human Genome Research Institute claims that, “*each of us has between 5 and 30 misspellings or alterations in our DNA: thus we could all be targets for discrimination based on our genes*” (Cook, 1999 p 159) . Even if in the future, we are able to accurately identify large numbers of the population at high risk of genetic disease and premature death, then “*not only will our understanding of “normality” have to be adjusted, but the risk base will be so broadened that insurance will become more possible and realistic*” (*Ibid.*, p 161).

Genetic testing and essentialism⁵⁰

One issue motivating and driving the debate and fear over genetic discrimination as invidious and unfair in the life insurance arena is the perception that genetic information alone is highly predictive of future health and life expectancy outcomes.

But as I have noted, such a perception is widely inaccurate because genetic information is not equally compelling and “*our knowledge of how genes produce clinical illness is still quite limited*” (Billings et al., 1992 p 476). Knowledge of the ways in which genes and environmental factors interact mean that we will be able to make more accurate predictions of outcomes, however there will always be a significant level of ambiguity (McConkey, 2004 p 58).

Kent offers the analogy of genetic information being portrayed in the media as if it were a “*train leaving a station and travelling along a track on which there were no sidings or diversions, gathering speed inexorably until it crashes into the buffers at the terminus to the great detriment and damage of all around*” (Kent, 2003 p 16). His point is clear: even where genetic tests offer certain information they cannot accurately predict one’s future health or life expectancy in any deterministic way. Genetic information is one source of knowledge that contributes to our general understanding of individuals lives (their health and life expectancy).

This is so even in apparently simple single gene diseases such as cystic fibrosis and HD, which were thought to be “*completely predictable on the basis of the presence or absence of a particular gene*” (Beckwith & Alper, 1998 p 208). For instance, the gene associated with cystic fibrosis – the CFTR gene – has more than 700 different known mutations scattered along the length of the gene.

⁵⁰ The view that we are to a large extent shaped by our genes (Everett, 2004)

Within the groups of individuals who test positive for monogenic diseases such as HD and PKD, the age range of onset and severity of disease varies considerably. HD is known to onset between the ages of 2 and 80 years old with the average age of onset generally being between 30 and 40 years of age (Myers, 2004), and some individuals with the HD mutation do not develop the disorder at all (Rubinsztein et al., 1996). Some individuals with PKD will die at an advanced age of something else. Many will die not even being aware that they had inherited the disease.

By far the majority of diseases have their basis in a combination of genetic and environmental factors. Even where a gene is highly penetrant “*the opportunity to intervene to reduce, prevent or treat disease alters the way in which the information should be treated. For example, in the case of familial hypercholesterolaemia or familial bowel cancer, knowledge of one’s genetic status can be positively beneficial in that it allows intervention and can prevent unnecessary disease and disability*” (Kent, 2003 p 17).

So although genes tell a very important part of the story, other aspects are also extremely relevant (Vineis et al., 2001), (Holtzman & Marteau, 2000). As I have noted, these include lifestyle choices and environmental factors but also mental health factors such as divorce, death of a partner, loss of one’s job, and physical health such as obesity, and other aggravating health issues. Even one’s postal code is a statistical indicator of one’s standard of living, and its impact on life expectancy (Lemmens, 2000 p 374), (Ministry of Health, 2005). To “*credit genes with a major independent role in the causes of complex diseases is scientific misjudgement of the way genetics affects disease risk – which is equivalent to assuming that adult-onset diabetes is caused*

mainly by predisposing genes, although clearly the disease is rare in the absence of obesity” (Vineis et al., 2001 p 709).

Whilst genetic tests offer new and diverse ways of understanding disease and estimating risk; knowing an individual’s genetic constitution will not solely or accurately predict their health and life expectancy outcomes and we should be extremely cautious of any claims that suggest otherwise.

An objection

Low et al, found evidence in the UK of unjustified cases of genetic discrimination and that some individuals had experienced difficulties in obtaining life insurance even though their genetic profile represented no adverse actuarial risk (Low et al., 1998). They concluded that this was primarily due to confusion and ignorance about genetic information resulting in inconsistencies in how such information is assessed in determining risk. An earlier study by McEwen et al, also verifies confusion about genetic information amongst life insurers and moreover found that many insurers did not have their own actuarial data and so it was “*difficult to discern the basis for the underwriting decisions that companies would make*” (McEwen et al., 1993 p 41). Does this mean that individuals are right to be fearful of invidious genetic discrimination in the area of life insurance? I do not believe it does.

The conclusions of Low et al and McEwen et al, do not suggest that individuals should be fearful of invidious genetic discrimination in the context of life insurance, but they clearly show that the problems of genetic ignorance and confusion evident in the UK life insurance industry must be addressed if people are to have confidence in the (fairness of the) underwriting process. When potential applicants are confident that insurers recognise the limitations of predicting life expectancy from the results of a

genetic test they will have little reason to be fearful of invidious genetic discrimination. As McEwen rightly notes, *“in light of the increasingly important role that genetics is likely to play in predictive medicine in the coming years, it will be helpful to increase the level of knowledge of these professionals”* (Ibid., p 44).

It is important to note that life insurance is offered to around 90-95% of applicants at standard or preferred rates in the UK, NZ⁵¹ and Canada (Nowlan, 2002),(Knoppers & Joly, 2004), and *“despite the introduction of innumerable screening, diagnostic and therapeutic technologies over the past century, the percentage of people who have been able to obtain life insurance has in fact risen”* (Raithatha & Smith, 2004 p 396).

Does the information resulting from genetic testing provide insurance underwriters with a uniquely accurate way of predicting the risk of premature death from genetic diseases? This discussion has argued that in most cases it does not and will not. The interplay amongst genes and in conjunction with environmental factors in terms of shaping health and life expectancy outcomes weaves a complicated and intricate tapestry: a tapestry that a genetic test cannot accurately predict in isolation from other non-genetic factors.

Conclusion

There has been growing concern that individuals will be unfairly discriminated against solely on the basis of their genetic constitution were life insurance companies to demand genetic testing as a condition of securing cover. As life insurers are in the business of risk minimisation and discrimination, and genetic tests allegedly offer a more accurate way of determining who is a ‘good bet’ and who is a ‘bad bet’ with regard to insuring, the fear is that those who carry certain genes will be unfairly

⁵¹ Personal communication with Deborah Keating, Investment Savings and Insurance Association of New Zealand Incorporated (ISI).

penalised. One may reason that unfairness stems from the fact that genetic risk is beyond an individual's control and therefore to be discriminated against on the basis of one's genetic makeup is invidious. However I have claimed that even where one is not responsible or to blame for their risk, discrimination is not necessarily invidious or unfair.

There is a common perception that the information resulting from a genetic test may accurately predict a person's future health. However most diseases are multifactorial in origin and environmental and social factors are being seen to play an increasingly significant role in conjunction with genetic factors. Highly penetrant single gene disorders can confer a heightened risk of premature death to a very small (and decreasing) group of individuals. I have claimed that a limited amount of cover could be extended to those who test positive for these disorders without such cover being excessively restrictive or prohibitive.

I suggest there are also a number of significant pragmatic reasons to think that insurance companies will not invidiously discriminate against large numbers of the population on the basis of genetic test results alone. Such companies work on the premise that healthy individuals will take out large amounts of cover and as they are low risk are attractive to insure. If it was perceived that genetic tests could accurately predict who was likely to die early and who would live a long and healthy life, the latter healthy individuals would surely reduce their cover, ask for premium reductions or neglect to take it out. Also, if it became clear that insurance companies were demanding that applicants have genetic tests, individuals may decide to pursue other types of financial security for their families and disregard life insurance altogether. Life insurance is not the only way an individual can guarantee financial security for their

dependents. As it is clear that genetic information is but one part of the story, making premium cover excessively prohibitive on the grounds that genes do determine future life expectancy would be self defeating and foolish.

We must not forget that life insurers already use information in the underwriting process and much of it has a strong genetic heritage. Applicants are obliged to disclose any information considered relevant to the insurance company in determining risk. Conversely the insurance company is obliged to be honest and diligent in assessing and interpreting such information. In most cases the information gained through genetic testing does not relevantly differ from other kinds of information gained through non-genetic tests.

Life insurance companies operate in the private arena and as such are one form of financial security for individuals and families. Whilst I have argued that discriminating against individuals on the basis of their genes is not necessarily invidious – at least in the area of life insurance - we should be sensitive to the needs of those who face a higher risk of disability or premature death through genetic disease. It also should be noted that private life insurance ought not to be the only way that individuals can provide financial security for their families in the unfortunate event that they should die prematurely from an inherited disease.

International studies indicating that adverse genetic discrimination has occurred, albeit in small numbers, highlights the need for a more informed life insurance industry, especially at the level where genetic information is assessed and decisions made about individuals suitability and attractiveness to insure. Once recognised by life insurers, I suggest that fear of invidious genetic discrimination is not warranted, thus we should not resist genetic testing by the life insurance industry.

Chapter 4. Predictive genetic testing of children for adult onset diseases and the psychological harms that may result

Introduction

It is alleged that children who are genetically tested for an adult onset disease may face a number of serious psychological harms regardless of whether or not they test positive for a genetic mutation. For instance, Wertz et al, claims that in families where a child returns a positive test result, he or she may be made a scapegoat who is abused by parents who are reminded of their own unacceptable traits (Wertz et al., 1994). The authors also claim that genetic testing may result in harms to the child's self esteem, harm to child-parent bonds and feelings of guilt (especially 'survivor guilt' in those who test negative).

They are not alone in their concerns. Within the literature a further number of psychological harms are said to eventuate if children are genetically tested for adult onset diseases. These include:

- 'Vulnerable child syndrome'. Where parents become over protective of children who had been ill or at risk but are no longer ill or at risk (Green & Solnit, 1964), (Wertz, 2000), (Friedman-Ross & Moon, 2000)
- The individual "*may feel doomed*" (Wright Clayton, 1997 p 242)

- Parents' attitudes towards the child may turn towards disappointment or rejection (CEJA, 1995)
- Feelings of unworthiness (Wertz et al., 1994)
- Lowered expectations within the family (Wertz et al., 1994), (Wright Clayton, 1997)
- Anxiety may be generated by the child's genetic status when it is known that the child will develop the disorder. The anxiety may cause worse problems than continued uncertainty (Clarke et al., 1994).

However there are also a number of psychological benefits that may result from testing children for adult onset diseases. These include:

- The opportunity for the child to adjust to the circumstances (Clarke et al., 1994), (Savulescu, 2001)
- The fostering of openness within the family (Clarke et al., 1994)
- The resolution of parental and family uncertainty and (for carrier status tests) ensuring that testing has been offered to the whole family (Clarke et al., 1994), (Savulescu, 2001), (CEJA, 1995), (Friedman-Ross & Moon, 2000), (ASHG/ACMG et al., 1995)
- Participation of the child in decisions about testing can promote the development of their autonomy (making more informed reproductive decisions, career choice, financial planning and end-of-life decision making) (Savulescu, 2001), (Malpas, 2005a)
- It is possible that harm to family members resulting from not testing could be greater than testing (for some parents, the provision of professional counselling would not resolve the anxiety of constantly anticipating indications for a degenerative disease their child might not even have) (CEJA, 1995)

- Parental expectations for the child's future can be more "realistic" (ASHG/ACMG et al., 1995), (Clarke et al., 1994), (Friedman-Ross & Moon, 2000)
- Psychological benefits resulting from practical preparation for the child's future, e.g. education, career, housing, financial security (Fryer, 2000), (Harper & Clarke, 1990)
- May lead to less societal discrimination as society recognizes that we all carry 'faulty' genes (Clarke, 1998), (Cook, 1999), (Lemmens, 2000), (Wertz et al., 1994).

Whilst there are a number of putative psychological harms alleged to result if children are tested for adult onset diseases there may also be a number of countervailing benefits. In the following discussion, I briefly note the conclusions and recommendations made by the Clinical Genetics Society in respect to their report 'The Genetic Testing of Children' and the response to it from the Genetic Interest Group. I then examine, in broader detail the following psychological harms; 'vulnerable child syndrome', 'limited horizons' and damage to the child's self esteem.

Discussion

Clinical Genetic Society Report (UK)

Over ten years ago the Clinical Genetic Society (UK) made a number of conclusions and recommendations about the genetic testing of children (Clarke et al., 1994). In regard to testing healthy children for adult onset diseases, the report generally advises against such testing where "*there are no medical interventions established as useful that can be offered in the event of a positive test result*" (Ibid., p 785). Although the primary justification for their decision was lack of a medical benefit, they also expressed concern for respecting the child's future autonomy ("*genetic testing should wait until the "children" requests such tests for themselves, as autonomous adults*")

(*Ibid*). The psychological implications of genetic testing were also recognised: “*it will be important to incorporate a social and psychological evaluation of the genetic testing*” (*Ibid*).

In response to the report, the Genetic Interest Group⁵² (GIG) stated a number of concerns about the various recommendations put forward. They claim that the report is “*overly preoccupied with psychological considerations and the harm that knowledge of genetic disorders can cause within families*” (Genetic Interest Group, 1995 p 490).

Families, they argue, need support and counselling but should be given credit for being responsible and having coping capacities. Parents are responsible for the well being of their children and generally have their best interests at heart. Furthermore knowledge about a genetic condition “*comes to be accepted as a fact of life in the same way that other issues are recognized to be individual and integral to any family*” (*Ibid*). Their response to the report also claims that children, even from an early age, are able to cope with information about themselves. It would seem *prima facie* that the authors of the GIG report would support the genetic testing of children for adult onset diseases.

It is surprising therefore that they do not support such testing. They defend PGT of children for childhood conditions (where medical intervention can provide a benefit) and uphold the rights of parents to make an informed choice of whether to have the child tested; however they claim, “*children should not be tested for adult onset conditions for which there are no pre-symptomatic medical treatments*” (*Ibid.*, p 491).

This is because the rights of an individual to exercise an informed choice later “*have to be held paramount*” (*Ibid*). The child’s future right to make an informed choice as an adult seems to trump all other considerations.

⁵² An umbrella organization in the UK for groups that support those affected by genetic disorders.

However they also suggest there are valid reasons to test children in the case of disorders for which there is no presymptomatic medical interventions. Their reasons include; *“possible freedom from anxiety, facilitating open relationships, and the parents’ need to secure the best environment they can for themselves, the child who will develop the disorder, and other children in the family. ‘Best environment’ might mean a house with suitable access, located near a school or hospital. It might also mean securing particular kinds of work”* (Genetic Interest Group, 1995 p 490). An obvious question then arises: if parents believe the best interests of the child are satisfied by testing them and knowing about a disorder that will develop soon (even if no medical benefit can be offered to the child) aren’t those same interests served when there is a longer period in which to come to terms with the likely onset of the condition? According to the report, apparently not.

The conclusions of the GIG report appear rather shortsighted. If it is the case that knowledge of genetic conditions *“comes to be accepted as a fact of life”* and children *“can cope with information about themselves from an early age”*, then why does the report conclude that these important factors should be overlooked in favour of future autonomy? If knowledge of genetic information comes to be accepted as a fact of life and children readily adapt to knowing such information, surely it is plausible that their developing autonomy may be enhanced and facilitated by genetic testing and subsequent disclosure of test results? This is surely why they recommend that at-risk children are tested for childhood onset diseases even when there are no medical interventions that are established as being beneficial for the child.

Furthermore one may claim, as I argued in chapter two, that not testing at risk children for adult onset diseases, hinders their developing autonomy by denying them crucial

information about themselves that is pertinent to their capacity for future decision making (in the areas of education, health care, insurance, and financial saving). They may resent the fact that they were not tested as children. One can imagine the young adult saying *'If you had had me tested when I was 8, I could have incorporated that knowledge into how I came to see myself without being fearful of it. Instead I have to face whether or not to be tested now when I am far more fearful of a positive result and what that knowledge may mean for the plans I have already begun to make for my future'*.

Although the GIG response to the Clinical Genetics Services report acknowledges but then appears to dismiss the importance of considering psychological factors (instead deferring to autonomy) in testing children, in the remainder of this chapter, I wish to focus on the alleged psychological harms for two reasons: First, it is surely important to consider the serious harms that are alleged to occur as a result of testing because we have an obligation to prevent children from being harmed. That includes considering harms other than the violation of future autonomous choice. Where harms are considered likely to occur, we ought to proceed cautiously, even where there is a lack of empirical evidence supporting the occurrence of harm. This is because of the seriousness of the likely harms.

Second, I do not believe it is obvious that respect for future autonomy trumps all other considerations as the GIG discussion suggests. As Fryer notes; *"the concerns about removal of autonomy and confidentiality may be overridden by the responsibility to do what is in the best interests of the child"* (Fryer, 2000 p 283). There are several points to make here: the psychological benefits to children (as a consequence of testing) may outweigh the harms; conversely, the psychological harms may be serious enough to

stand as a strong reason not to test children, the child may wish to undergo testing for herself, and her arguments may be reasonable and persuasive and finally, the child's parents may be best placed to weigh what is in the child's best interest and autonomy may lose out if other interests are given more weight.

In the following discussion, I critically reflect on the psychological harms that are alleged to occur if children are genetically tested for adult onset diseases.

Vulnerable child syndrome

Forty years ago Green and Solnit (Green & Solnit, 1964) coined the term *vulnerable child syndrome* to refer to those children who, having experienced a serious potentially life threatening illness early in their lives, are seen by their parents as being “*medically vulnerable long after they have fully recovered*” (Allen et al., 2004 p 267). Such children “*often react with a disturbance in psycho-social development*”, and are provided with fewer opportunities for them to gain independence than non-vulnerable children (Green & Solnit, 1964 p 58). Disturbances in psycho-social development include difficulties with separation (in extreme cases where the child and mother never separate), infantilization (where the parents are overprotective, overly indulgent and over solicitous, and where the child is overly dependent, disobedient, irritable, argumentative and uncooperative), bodily concerns (hypochondrial complaints such as recurrent abdominal pain and headaches or infantile fears) and school underachievement (where the child has learning difficulties) (Ibid., p 60-62). They summarize in their study that, “*parental reactions to an acute life threatening illness in a child may have long term psychologically deleterious effects on both parents and children*” (Ibid., p 63). Children who are perceived as vulnerable also consume a disproportionate share of child health care services (Boyce, 1992).

Who are these vulnerable children? According to Green and Solnit there are many factors that may predispose children to being perceived as vulnerable. These include; children born with a congenital abnormality, children born to older parents who had resigned themselves to being childless, children who are premature or have an acquired handicap such as epilepsy, the child who already has a truly life threatening illness, the child whose parents were told during pregnancy that the foetus may die, children whose mothers suffered from post partum depression, the child whose parents cannot have more children due to a hysterectomy or sterilization, the child whose parents are grieving for the death of another child or close relative, children who inherit a family disorder (such as cystic fibrosis or muscular dystrophy), children whose parents are strongly ambivalent towards them (the mother of a baby born out of wedlock who had strong feelings of not wanting the child), and finally the child whose mother has a strong psychological need to find something physically wrong with the child (such as Munchausen Syndrome by Proxy) (Ibid., p 62-3).

Since the Green and Solnit study, many other researchers have also found evidence of vulnerable child syndrome. Children who were born prematurely but were healthy at age three years had mothers whose sense of vulnerability concerning their children was greater than mothers whose children had been delivered at full-term (Perrin, West, & Culley, 1989). Kemper et al, found that “*many mothers of otherwise well, full-term infants consider jaundice a serious illness*” and that jaundice was a “*significant risk factor for quitting breast-feeding*” (Kemper, Forsyth, & McCarthy, 1989 p 776). They also found that the mothers of jaundiced babies were apprehensive about leaving the baby with anyone else in the first month (even the father of the baby) and that such mothers utilized health care services more excessively than the control group.

Surely these findings are not surprising or unexpected. Children who are born with or come to develop a serious illness that may result in their early death or disability require extensive and possibly expensive care, ongoing attention and support from both medical professionals and parents (and other family members). It is likely that parents, especially parents of first children, experience a number of emotions – grief, fear, helplessness, anger, guilt, shock, disbelief – during the initial stages of diagnosis and treatment and so come to view their child as vulnerable. It may help if parents are told that such feelings are normal and understandable. As Green and Solnit note, “*the physician may point out that after a child’s recovery from a severe illness, many parents have a natural inclination to wonder if they could have prevented it in some vague way and since the child was so sick, there is a natural inclination to treat him specially, a tendency that actually becomes disadvantageous to both the parents and the child*” (Green & Solnit, 1964 p 66).

Doctors have an obligation to impart clear and relevant information to parents of ill children however, “*the designation “critically ill” should be employed only when clearly indicated*” (Ibid., p 65) because parents who are inadequately informed about the disease (and the implications for their child) may be more likely to respond by perceiving their child as vulnerable. This is where extensive support and education of parents with seriously ill children could help in reducing the numbers of children seen as vulnerable (by their parents).

At the time the term vulnerable child syndrome was first coined, PGT of children for adult onset diseases was unavailable. If a child was diagnosed with a genetic condition it was generally because they had a disorder that had already begun to onset (in some very rare situations a child may develop an adult onset disease in childhood). For

instance, a child who experienced rapid muscle degeneration - had great difficulty sitting and learning to walk - may indicate a diagnosis of muscular dystrophy, especially where the condition is known to exist within the extended family. Likewise a child with cystic fibrosis would come to exhibit symptoms of the disease in childhood (very salty-tasting skin; persistent coughing, at times with phlegm; wheezing or shortness of breath; an excessive appetite but poor weight gain; and greasy, bulky stools (Cystic Fibrosis Foundation, 2004)). However children who were at-risk for conditions that would not generally develop until adulthood - such as HD and myotonic dystrophy - were not genetically tested for their at-risk status as such tests were not available. Parents may have subconsciously identified a child as being vulnerable where a disease was manifest within a family, but such identification was not the result of a child being tested and found to be positive for the disease, or of a child being singled out by medical professionals as being at risk of illness or premature death. The vulnerable child, in this case, was singled out because the parents may have 'had a feeling' the child was at-risk (perhaps the child resembled an older affected relative). One benefit of testing at-risk children is that a negative test result may dispel parental fears of their child being vulnerable. However it is equally important to recognise that a test result showing the child does carry a genetic mutation may confirm the parent's view of the child's vulnerability.

So how serious is the claim that children who are tested for an adult onset disease may come to be perceived as vulnerable by their parents? Central to the studies undertaken by Green, Solnit and others, is that children who are perceived by their parents as being vulnerable and where vulnerable child syndrome was observed in the family are those children who experienced an acute, potentially life threatening illness early in life from which they recovered, but from which they were expected to die prematurely. Boyce

states that the apprehension caused by the threatened loss of a child may permanently alter the way a parent perceives and interacts with a child (Boyce, 1992).

However, healthy children who are at risk for an adult onset disease do not face an acute, potentially life threatening illness early in life. They will not develop the disease in childhood, nor are they expected to die prematurely (in childhood) from the disease if they test positive for the condition. These are children for whom the disease will not develop for a significant number of years if at all. They may die of something else before onset begins. It is conceivable that children who face a life threatening disease early in life and are also at risk for an adult onset disease may be more at risk of vulnerable child syndrome. In such a situation, the parent's perception of their child being vulnerable is more likely grounded in the child's early illness and possible premature death, rather than their risk of a disease that will not develop until adulthood. This is where an accurate and clear understanding of the condition may help allay fears of a child's vulnerability, although it may be that in such circumstances, the testing of a child for an adult onset disease is not appropriate or recommended. This could be determined during professional counselling and consultation well before testing was undertaken.

Rather than support the claim that PGT not be performed because parents may come to perceive their child as vulnerable and so access more health care or prevent the child from participating in various activities, we should undertake to educate parents about the progression of the disease and what testing will achieve. Parents who want their children tested for a condition such as HD or PKD do so knowing that one of the child's parents carries the gene(s) responsible for the disease⁵³. Therefore they are aware of the

⁵³ Where parents do not know of their own risk status, children should not be tested before them, unless there are clear medical indications that intervention would benefit the child. This is because if a child

disease, its manifestation within the family, and the implications for them as a family. At this point it can be emphasized that the child is currently healthy and not at risk of dying or disability. This may eliminate the worry of vulnerable child syndrome arising with parents whose child returns a positive test result. Alternatively, informing parents about the benefits and burdens of genetically testing their children may cause them to defer testing until the child can make an informed decision for themselves. We should respect such decisions.

Parents who know the disease exists within the family, know that one of them has tested positive for the condition, believe that testing is in the best interests of the child and the family, and believes that the child will benefit from being tested are unlikely to perceive their child as vulnerable because they understand the disease for themselves and how it impacts on their family.

Limited horizons

Wertz et al, state that “*perhaps the most frequent reason*” given to request testing is that parents can plan for their child’s future (Wertz et al., 1994 p 878). However the authors point out that those parents usually envisage the benefits of a negative test result and not the potential harms that may come from a positive test result. They claim “*planning for the future*” may become “*restricting the future*” by shifting family resources away from a child with a positive diagnosis. Parents may not expect a child who tests positive for a genetic disorder with a shortened life expectancy to train for a profession. After all, why bother financing a child through expensive (and extensive) tertiary training if their disorder is expected to onset in mid adulthood, and so cut short

tests positive, it is then certain that the at-risk parent also carries the gene. Parents should know their own genetic status first and have considered the implications for themselves before having their children tested.

their career? Such children grow up in a world of limited horizons and may be psychologically harmed even if treatment is subsequently found for the disorder (*Ibid*).

The authors' claim that the most frequent reason parents give in wanting genetic testing for their children is so that they can plan for the child's future is both reasonable and understandable. Parents generally want what is best for their children and if a child is at risk for a condition that is manifest within the wider family, parents may sincerely believe that a test confirming their child's risk status (either positive or negative) is in the best interests of the child and family (even when the condition is both untreatable and unpreventable). This may be for a number of important reasons. Such knowledge may engender the fostering of openness within the family, presenting the child with the opportunity to grow up in knowledge of the disease and be able to adjust to the circumstances as they mature and begin to make important life goals. It may also resolve parental and family uncertainty, and allow for realistic expectations for the child's future. 'Planning for the future' may entail a number of different factors: it may involve financial security in the way of an insurance scheme or savings, financial support for education (high school and/or university study), the undertaking of various extra curricular training – musical, mathematical, sporting or academic – and, for parents, whether to have more children and when, how to allocate resources that are available to the family, whether to move closer to extended family or health care services, and decisions about work commitments (overseas travel, hours worked).

The authors worry though, that resources may be shifted away from children (with a positive diagnosis), thus restricting their future options. Wertz quotes that several geneticists in an international survey reported that "*parents had requested testing of children for the Huntington gene, in order to decide whether to save money for the*

child's college education. If the child had the gene, the parents would not waste family resources" (Wertz, 1998 p 273). Wright Clayton also raises a similar concern. She comments that a parent may request testing "*with the expressed intention of not sending her child to college if she has the mutation because 'it would be a waste of money'*" (Wright Clayton, 1997 p 243). The fact that some - perhaps only a very small number of - parents may request testing to confirm whether or not they should save for the child's education, may strike some as uncaring and callous. But if we believe that parents generally want to do what is in their child's best interests, then Wertz's interpretation regarding the geneticists' comments may be misleading. A parent may comment that they would not save for their affected child's college education, intending instead to use that money to ensure that the child had a very positive and memorable childhood. One can imagine the parents who, knowing the child may only live until his or her early adulthood, devote their energies and resources into supporting and enabling the child's self esteem and confidence, and providing the child with opportunities they may otherwise not have had. For instance; travelling the world, regularly spending more time with older extended family members, actively pursuing a child's passions and hobbies, deciding not to send the child to boarding school, doing more together as a family, or simply spending more time with the child by limiting work hours.

In a study of parental attitudes regarding newborn screening (for polycystic kidney disease and Duchenne's muscular dystrophy), the authors note that many parents stated "*if they knew (the child had tested positive), they would try to give their child more opportunities when he was young in terms of travel or even quality time together*" (Campbell & Ross, 2003a p 211). One parent in the study commented, "*when you hear that you're not going to have your child at a certain point, then it changes you. That*

has nothing to do with discipline and those things, but it has a lot to do with quality of life and what you do with that child” (Ibid., p 212).

Rather than focus on the child’s long term future with respect to saving for their education parents may prefer to invest their finances and energies into making their child’s life as happy as possible whilst he/she is still young (hence the comment that saving for their child’s college education was a waste of money). When a child has inherited a condition that has passed down through the family, it is difficult to imagine decent parents calculatingly depriving the child of resources and opportunities. Surely it is more plausible to imagine that parents whose children are at risk of a disorder that will not develop until adulthood and for which nothing can be done to medically benefit them, would overindulge their children rather than withdraw resources away from them.

Some parents may not expect a child who tests poorly in an academic exam to train for a profession, but that is no reason to prevent children from being tested for their academic aptitude. Likewise, some parents may not expect a child who is diagnosed with dyslexia to train for an academic profession, but that is not a reason not to test children for a learning disability. Of course one could respond that these are treatable conditions and adult onset diseases currently are not. Testing for the former conditions offers the prospect of being able to resolve the child’s learning problems. In reply I suggest that the point of testing a child for a learning disability, their academic aptitude, or their genetic makeup (with regards to a late onset disease) is to benefit the child both now and in the future. We recognise that the ways in which we treat children now has important and significant implications for their future well being. Whilst we cannot prevent or cure many adult onset diseases, the knowledge that comes from testing may

benefit children and their families in many different ways and we should not ignore or underestimate those benefits.

Whilst there may be a few parents who would request testing of their children in order to distribute family resources away from them if an unfavourable result eventuated, many more, I suggest, are likely to implement increased support and assistance for their children if they test positive. As the GIG report so succinctly comments; *“Because a few parents may not have the best interests of their children at heart, or have a different perspective as to what those best interests may be, this is no reason to frame recommendations as if all children require protection from parents”* (Genetic Interest Group, 1995 p 490).

Wertz raises the harm of a ‘limited horizon’ in order to strengthen her claim that we ought not to test children for adult onset diseases. However there is little evidence to justify such a position, other than a few comments from several geneticists in an international survey of nearly 3000 genetic service providers. It is interesting to note that of the 2903 genetic service providers who completed this survey, a significant number of them (in Eastern Europe, Asia, Latin America and Southern Europe) thought parents should be able to have minor children tested for late onset diseases (Wertz, 1998 p 279 Table 3). It is interesting because Wertz claims that parents may limit their child’s future by testing, yet a considerable number of geneticists throughout the world believe parents should be able to have their children tested, which may indicate that the ‘limited horizon’ view is not widely supported by those expert in the field. For surely if professional geneticists’ believed that the parents who requested testing for their children were to limit their children’s futures by withdrawing resources away from

children, they would be very reticent about supporting parents who wanted their children tested.

A recent survey of future lawyers and physicians in Switzerland, presented with the case of a patient with HD and her two sons (aged 10 and 16), found 91% of the fifth year students thought the adolescent son should have the chance to have a genetic test for HD. There was less support for testing the 10 year old son for HD. Almost 44% of the law students and 30% of the medical students were in favour of testing the child for HD (Elger & Harding, 2006). Some of the students justified their responses by stating that the test should be voluntary and only considered if the child 'desires the test' (Ibid., p 163). Some of the students responded that the parents ought to consent to testing and they should be the ones to disclose the results to their children. Although the survey was limited both in the scope of questions asked and the reasons given for their responses, it clearly shows support for the testing of children by future doctors; some of whom may go on to specialize in pediatric medicine.

If we take as reasonably accurate the view that parents generally have their children's best interests at heart then, when they state that they want their at risk children tested because it would help them in planning their child's future, we surely should listen carefully to such requests. It may well be that such requests are sincere and considered expressions of what is in the child's best interests.

Damage to the child's self-esteem

Clarke and Flinter claim that PGT of children could "*affect the deepest levels of self-esteem*" (Clarke & Flinter, 1996 p 166). Wertz et al, worry that a positive diagnosis may result in loss of self-esteem (Wertz et al., 1994). The Clinical Genetics Society report noted earlier concludes that "*the potential harms caused by childhood genetic*

testing might include damage to the child's self-esteem..." (Clarke et al., 1994 p 786), and Bloch and Hayden claim that *"the self-esteem and sense of worth of a developing child may be profoundly and negatively affected"* (Bloch & Hayden, 1990 p 2).

It is clear from these statements that the issue of children's self-esteem in relation to PGT is an important one to consider. However none of the authors give any indication of what self-esteem entails, how a child's self-esteem is damaged or lost as a result of a positive diagnosis, nor exactly what it is that would damage the child's self-esteem. For instance, is it the knowledge and disclosure itself, or the way in which the child is subsequently treated by the family? The authors do not provide any evidence that children's self-esteem may be damaged by the disclosure of genetic knowledge. It is simply assumed that this will occur if children are genetically tested.

What is self esteem and what does it mean to possess it? According to Rawls, self esteem has two aspects; first, it *"includes a person's sense of his own value, his secure conviction that his conception of his good, his plan of life, is worth carrying out"*. Second it *"implies a confidence in one's abilities, so far as it is within one's power, to fulfil one's intentions"* (Rawls, 1971 p 386). This position is similarly held by Coopersmith who asserts that a person who has self esteem believes in their own worthiness, and that this is expressed in their attitudes about themselves (Coopersmith, 1967). He claims that when individuals with high self esteem face adversity, *"they are less likely to have their confidence shaken than are persons who are fearful and unsure of their abilities"* (Ibid., p 248), and that *"there is evidence that the child with high self-esteem is more active, enterprising, and competent"* (Ibid., p 262).

Nuttall claims that *"self-esteem is the pride that a person has in himself or herself"* (Nuttall, 1991 p 1). Children, he argues, feel good or bad about themselves because of

what happens to them by those involved in their daily lives. *“People who are important to children have a great effect on the development of self-esteem in children”* (Ibid., p 2).

The development of self-esteem can be given in terms of the following conditions:

- Total or near total acceptance of the children by their parents/caregivers (parents are concerned for their children’s welfare, are willing to exert themselves on their behalf and are loyal sources of affection and support)
- Clearly defined and enforced limits (openly expressed rules and restraints provide a framework for discussion and hence require less supervision and restrictions. Parents who have definite values, who have a clear idea of what they regard as appropriate behaviour, and who are willing and able to present and enforce their beliefs)
- Respect and latitude for individual action that exists within the defined limits (Coopersmith, 1967).

How might the knowledge that she carries the genes for a disease that will not develop until adulthood damage a child’s self-esteem? Perhaps those who object to testing of this sort worry that disclosure of such information may distort the way in which the child judges her own worthiness or value. In other words, she understands the knowledge to mean that she is unworthy or valueless in some particular way. Perhaps this may result in her having feelings of worthlessness because she views herself differently (negatively) to her other siblings or friends. Or maybe she will judge herself to be somehow blameworthy for the genes she carries which in turn may lead to feelings of low self-esteem.

However the child who feels shame, worthlessness or has little pride or value in herself or her abilities because of her genetic test result has not come to such a position independently. She will certainly be influenced by how important people in her life, such as her parents and siblings, react to the information, especially if their responses to the test result are negative or pessimistic. Thus the family environment is a crucially important factor in how the child comes to judge herself and her feelings of pride in her abilities and talents. It is significant to note that whilst the information given to the child is important⁵⁴, the ways in which the family respond and deal with the knowledge is critical for the young child's developing self-esteem. If she feels valued, loved and secure and the knowledge simply becomes a part of her life then it is plausible to suggest that such a child will mature with high self esteem.

Children in families who are treated with respect, are accepted, are the recipients of affection and support, know that restrictions and rules are in place, and that there is latitude in terms of expected behaviour and action are, I believe, less likely to experience a loss of self-esteem were they to be genetically tested for a hereditary condition. This is because they are situated in strongly supportive and caring environments. Where children grow up valued, respected for who they are, regardless of their genetic inheritance and are shown affection and acceptance, then self-esteem flourishes and the child's attitudes towards herself are positive and healthy. *"The conditions of treatment associated with the formation of high self esteem are likely to be marked by high levels of activity, strong and independent convictions, and differences of opinion that contribute to self definition, provide social stimulation, and lead to increased communication between family members"* (Coopersmith, 1967 p 253). Where an inherited adult onset disease is manifest in such a family, the ways in which the

⁵⁴ That she can understand what is being said to her and is not distressed by being given too much or too little information (Edwards & Davis, 1997).

adults respond to the genetic knowledge has significant impact on how the children respond to it also. Open and honest communication between family members surely promotes rather than hinders the child's self-esteem.

Koocher found that pediatric cancer patients who were able to discuss their fears and concerns about the disease and its implications were much more able to engage in the treatment process. They were also less anxious and had higher levels of self control (Koocher, 1986). Gibbons states that "*open communication allows the child an opportunity to discuss fears and apprehensions and therefore to relieve the burden of erroneous assumptions. The child can then be assisted to work through fears and to find more effective coping strategies*" (Gibbons, 2001 p 56). Even though Koocher and Gibbons were discussing terminally ill children, their emphasis on the importance of open and honest communication with children about their illnesses is a valuable contribution to the issue of PGT of children. Communication with children about their illness - whether it is a terminal childhood illness they will likely die of, or an illness they will recover from, or their risk of developing a disease later - is important not only to prepare them for the treatment to follow (hospitalization, invasive procedures, time away from family and friends), but because being honest with children is important and central for their developing self-esteem. It also powerfully conveys to the child that they are respected as an individual whose future well being is recognised and acknowledged.

Conclusion

A number of serious psychological harms are alleged to result if children are tested for adult onset diseases, thus genetic service providers generally recommend that children not be tested unless there are clear medical benefits to the child. Some commentators

are against testing of this kind altogether (Bloch & Hayden, 1990), (Ball, Tyler, & Harper, 1994) and others advise caution (Clarke & Flinter, 1996).

In this discussion I focused on three putative harms alleged to occur if children were tested for adult onset diseases. In the case of vulnerable child syndrome, I have claimed that because children who test positive are not ill and will not die prematurely in childhood it is unlikely that they will be perceived as vulnerable by their parents. If parents are knowledgeable and informed that their currently healthy children are not ill, and are educated about the disease itself (prior to genetic testing), it is unlikely that their children will be perceived as vulnerable and deprived of opportunities or become a burden on health care providers.

Wertz et al, state that testing children to assist in planning for their future may actually mean restricting the child's future in an adverse way. Parents may decide, upon a positive diagnosis, to withdraw resources away from their child. The authors refer to a geneticist who commented that several parents had requested testing so that they could make a decision about whether to save for their child's college education. Such a request appears callous and uncaring. If most parents want what is in their child's best interests then it seems unlikely that parents would request testing to determine whether saving for their child's education was a waste of money that could be better spent on other children or themselves. I claim it is more likely that parents who request testing in order to plan for their child's future do so to expand opportunities for their child.

Genetic counselling and support that accurately and thoroughly sets out the known progression of a disease is far more likely to help parents make realistic plans for their children's (future) lives, than lead to a withdrawing of resources and support from such children. Where professional support thought it likely that certain parents would

withdraw resources away from their affected children, a decision to test may be appropriately withheld, in the best interest of the child.

Finally I considered the claim that testing children may result in their self-esteem being damaged by the disclosure of such information. I suggested that the child who is shown acceptance and respect, and is encouraged to communicate openly and honestly with her parents, comes to develop high self-esteem and self valuation. Knowledge that one has tested positive may not damage the child's self-esteem if she grows up always having known and been able to incorporate such knowledge into how she sees herself (in the same way that some children have always known that they were adopted and have come to accept that fact as a part of who they are). "*Children with high self esteem appear to learn quite early that they must respond to the challenges and troublesome conditions they encounter*" (Coopersmith, 1967 p 261). Children who have developed high self-esteem, and are situated in supportive and empowering families are perhaps less likely to experience damaging of their self-esteem because they already have high self esteem. They may also be able to successfully incorporate such information into their own judgments about themselves.

In conclusion, whilst I do not suggest that all at-risk children should be tested for adult onset diseases we ought to consider acquiescing to some parental requests for such testing because the putative psychological harms may not be as significant or likely as initially thought. This is because parents generally have the best interests of their children at heart and if they are properly supported and educated about PGT and the possible consequences, then the risk of psychological harms occurring may be ameliorated.

Chapter 5. Telling at-risk, asymptomatic children an adult onset disease exists within the family but refusing to test them for it. Why not test?

Introduction

Genetic service provider guidelines recommend that children are told a hereditary disease exists within the family. The HGSA states, “*it is recommended that the child is made aware of genetic conditions in the family, which may impact on them, and that the child be reared with this knowledge. This enables the child to make a free choice about genetic testing when a competent adult*” (Human Genetics Society of Australasia, 2003). The American Medical Association also claims that if parents discuss the “*child’s risk with the child, they will be able to explain to the child that testing will be available at the discretion of the child when the child reaches maturity*”(CEJA, 1995). Although the Clinical Genetics Society working party report generally advises against the genetic testing of children for adult onset diseases “*this does not entail our recommending that families should avoid discussing the issues with younger children*” (Clarke et al., 1994 p 785). The guidelines are clear: children ought to be told about genetic conditions that exist within the family. However all agree that they should not be tested for adult onset diseases until they are old enough to make an informed choice for themselves.

In this chapter I begin by considering why it is important to tell children genetic information which will go on to impact their lives in a significant way. Then I ask the question, if it is important to inform children that they are at-risk for a disease that exists within the family, why shouldn't they also grow up knowing whether or not they carry the genetic mutation? It is important to note however, that some individuals at risk for late onset diseases such as HD are not aware of their risk status as the disorder may not have been known about or discussed within the family. For these individuals the luxury of choice about whether to be tested is not available⁵⁵

I. Disclosing information to children: why tell them?

Why is it important to tell children about genetic conditions known within the family? The HGSA (and others) claim that knowing such information, "*enables the child to make a free choice about genetic testing when a competent adult*". Between the ages of sixteen and eighteen individuals are considered mature enough to understand what such knowledge means for them and with support, can come to an informed decision about testing. But one could plausibly suggest that older children could be told at eighteen their at-risk status and this would still enable them to make a free choice about testing (they would have the rest of their lives to make that choice). Telling individuals in late adolescence that they are at risk for an inherited disease however, may shatter the future they have begun to create and envisage for themselves. By this age individuals have begun to make definite plans about what kind of career they may follow; whether (or not) they will continue with tertiary education or follow a particular career path. Some may have significant partners in their lives and be contemplating starting a family, others may be more carefree about their future, yet still have strong ideas about its direction.

⁵⁵ I would like to thank Dr Angus Clarke for making this point.

It is interesting to note in a study that at-risk individuals who declined to be tested for Huntington's disease were more likely to have learnt about their risk status during adolescence (van der Steenstraten, Tibben, Roos, Kamp, & Niermeijer, 1994). These individuals "*suffered severely from the burden of HD*" and were "*significantly more pessimistic about their future*" (*Ibid.*, p 623). This may indicate that adolescence may not be an ideal time to disclose important genetic information regarding one's risk (Genetic Interest Group, 1995).

Even though there may be strong reasons to think that disclosing certain genetic information to adolescents may not be a good idea, it is certainly not clear that disclosing adult onset disease risks to young children enables them to make an autonomous choice to be tested later as adults; the child may be told once and it may not be discussed again by family members, alternatively, the child may not fully understand what such information means. It may only confuse or worse, frighten them. Simply telling a child about a genetic condition within the family is not enough to satisfy the claim that disclosure (of risk) facilitates future autonomous decision-making as an adult. I will return to this point later in my discussion.

Although genetic service provider guidelines claim that disclosure to children of genetic conditions within the family respects the child's future autonomous decision-making capacities I suggest there are other important reasons why disclosure to children is important.

Secrets and respect

"Secrets are powerful things. Secrets within any family distort reality, undermine trust, and destroy intimacy. Secrets create exclusion, destroy authenticity, produce fantasies, evoke fear, and kindle shame" (Schooler & Norris, 2002 p 10).

Keeping secrets from children especially where the secret involves knowledge that may adversely or significantly impact upon the child's life may result in more harm than good (if the secret is exposed to her). Secrets are common in families and may be kept from individuals for a number of reasons: they may be held by one member of the family only (knowledge that one had an extra marital affair), they may be held by two or more family members who keep at least one another person in the dark (knowledge that a child was adopted), and finally shared family secrets where the secrets are held within the family and are never disclosed to outsiders (the past misdemeanours of certain family members (Karpel, 1980)). According to Selvini, a secret "*implies intentional concealment of some information important and relevant to the one from whom it is held*" (Selvini, 1997 p 317). Genetic information is relevant and important to children because it is crucial information about them, as well as other family members, and will possibly go on to have a significant impact on their future lives. After all, the fact that something has been kept a secret implies that its revelation will have a significant impact on those from whom it has been concealed.

Concealment of knowledge denies a child fundamentally important details about themselves and, "*long experience demonstrates that hiding information from children usually does not work and that efforts to keep secrets leave children feeling deceived and abandoned*" (Wright Clayton, 1997 p 246). R. Bender notes that "*when you are confronted by a policy of secrecy, and too often also by the message that you ought to feel guilty and ungrateful for wanting to know these things, they can rankle and their importance can grow into obsession. The effects of secrecy can be very harmful*" (as cited in Griffith, 1991).

In a study by Skirton, she recounts the anger expressed by a woman frustrated that her mother persisted in hiding genetic information which she felt should have been shared. The daughter believed that her mother's insistence on keeping information hidden amounted to her controlling her and her siblings' lives (Skirton, 1998). Parents who know certain genetic information, and who choose not to tell their at-risk children exert power over them, and "*withholding the knowledge from the child also results in a withholding of the power to make informed choices*" (Skirton, 1998 p 110). Of the individuals studied, "*those who felt that information had been deliberately withheld from them were deeply resentful and expressed anger and feelings of disempowerment as a result*" (*Ibid*).

Wright Clayton claims that children are "*not well served by being voiceless until the age of majority*" (Wright Clayton, 1997 p 244). She further continues that "*keeping information from them is also an affront to their identity*" (*Ibid.*, p 246). Telling children about a disease risk within the family may remove some of their uncertainty especially when they are confronted with extended family members who are exhibiting features of the disease. Children are often aware of tensions within the family without being told any specific information; they may know something is wrong yet be unsure what it is. Telling a child about what is happening within the family (in a way she can understand) respects her as an individual who has an interest in being informed about information that will go on to significantly influence her future as an autonomous agent.

Knowing that grandma has polycystic kidney disease and has to go to hospital regularly for dialysis treatment may reassure her grandchildren that she is being looked after especially if the disease is talked about openly. Being able to discuss it candidly and honestly reduces the likelihood of children feeling that information was hidden from

them, which may engender feelings of distrust and betrayal if they find out later; for instance, *“If they didn’t tell me about this risk in the family, what else haven’t they told me?”* It is also possible that not telling children the truth about a disease in the family communicates to the child that the disease is so terrible that it must not be discussed.

“It is a short jump from that message to an understanding that” the disease is something to dread and fear (Griffith, 1991 Sec 12, p 15). In a study that addressed the issue of disclosing information to young children diagnosed with cancer, the authors note that *“lack of disclosure may communicate the unintended message that the disease is a morbid, frightening secret to be worried about and that it is so toxic and dangerous it cannot be discussed openly”* (Claflin & Barbarin, 1991 p 118).

Of course whilst there may be differences in disclosing to a young child that they have cancer (and may need certain invasive treatments and time spent away from family and friends), and disclosure that a disease is manifest within the family, I suggest they are not relevant differences. Both kinds of information will go on to have profound implications for the child’s life both now and in the future.

Children need to be able to make sense of the information given to them because the disease may already affect those around them (older relatives, parents, siblings), and they need to be able to incorporate such an understanding of what it will mean for their own lives. *“One very important factor is whether children do or do not have knowledge of the relevant genetic condition based on personal experience, perhaps of a close relative suffering severe problems from the condition. Children with experience of serious illness or disability and treatment, even if they are well below average at school can have high levels of competence concerning decisions about their health care”* (Alderson, 1998 p 34). We simply cannot assume that children are not capable of

understanding genetic knowledge, or that they are better off not being told when they may have experienced the consequences of genetic conditions within their families. Knowing why an affected family member reacts and responds to the disease in the way they do may help children understand the family circumstances better.

Facilitating self identity

It is important to disclose certain pertinent information to children in order to help them successfully incorporate that information into their developing self identity (how they see themselves in the family and how others see them). Such information has important implications for the plans and goals they are beginning to formulate. It may also allow them to come to terms with what the information means for them as they begin to take their place in the world. In the study undertaken by Skirton (noted earlier), she states, *“the advantages of telling a child (genetic information) gradually as the opportunity presents itself or as questions arise was stressed by a number of respondents, who felt that there were benefits in being able to absorb the information slowly and so gradually adjust to the altered potential of life”* (Skirton, 1998 p 108). Such opportunities also communicate to the child that the disorder is a part of life. It may be something the family wishes dearly they did not have, but sharing the knowledge and working through what it will mean for them, both as an individual and part of an extended family, communicates to the child that this knowledge can be spoken about and is not to be hidden, feared or suppressed .

The GIG response to the UK Clinical Genetics Society report states (in regard to pre-symptomatic diagnosis of childhood onset conditions) that *“although the vast majority (of families) would prefer there not to be a genetic disorder in their family, (such) knowledge comes to be accepted as a fact of life in the same way that other issues are*

recognized to be individual and integral to any family. It is also our experience that children can cope with information about themselves from an early age and that it is much more often the adult who has a problem in giving information” (Genetic Interest Group, 1995 p 490).

Biological origins

Disclosure about one’s adoptive and biological origins is considered crucial for the child’s developing self esteem and identity. From the vast amount of research that has been undertaken with adoptees, we know that telling children the truth about their adoption at a young age is crucial if they are to successfully incorporate that knowledge into their lives and develop a high self esteem (Griffith, 1991). In a study undertaken by Triseliotis, *“adoptees who were told or found out (about their adoption) when over the age of about ten felt this deeply and it had a profound adverse effect on them.*

Revelation at this late stage had a stunning effect, shaking their entire life and self-image, leaving most of them confused and bewildered. They felt the need to reassess their whole life and to start ‘re-discovering’ themselves. The revelation shook their whole being and appeared to upset both the physical as well as the mental image of themselves” (Triseliotis, 1973 p 20). This is also confirmed by Griffith; adoptees that are not told by adolescence *“are much more prone to have greater self-identity conflicts. If not told till after their main self-identity structure is laid down, then they have built the structure on some false foundations. Much pain and turmoil can be caused by late telling” (Griffith, 1991 p 4-5).*

Even though they are generally unable to truly understand what it means to be adopted at a very young age, children who were told young and grew up having ‘always

known', coped much better than children who were not told until they were older (Triseliotis, 1973).

Disclosure of disease risk may also benefit children when they are told young as opposed to being told as adolescents or adults. In the Skirton study she noted that respondents "*ventured the opinion that it is easier for a young person to deal with the news of risk than it would be at an older age*" (Skirton, 1998 p 108).

Chronic conditions

Imparting important information to children is not restricted to disclosing knowledge about adoption and biological origins. Children who have chronic⁵⁶ conditions also need to be told about their illness. "*Information is central to preparing children for medical procedures in order for them to develop realistic expectations and make sense of what is to happen. Being informed enables them to be actively involved in their own treatment and to communicate their needs to others. Giving information is also one way of challenging or correcting misconceptions and inaccurate beliefs*" (Edwards & Davis, 1997 p 118). One of the important aims of counselling chronically ill children is to empower them "*to develop their own problem-solving strategies, and as a consequence help them to feel more in control and to feel better about themselves*" (Edwards & Davis, 1997 p 66). Central to this process is communication, both to the child and their families.

To briefly summarize the discussion so far; I have discussed the view that children ought to be told about their at risk status sooner rather than later in their lives.

⁵⁶ Chronic illnesses are those that cannot be cured and are characterized by their long duration. They may differ in how they affect a child's life and by their severity. For instance, disorders like phenylketonuria and cystic fibrosis are usually diagnosed in the first few weeks of life, whereas some chronic illnesses occur during childhood (diabetes, asthma and epilepsy), and may develop suddenly and without warning (Eiser, 1993).

Traditionally such disclosure has been seen as respecting the child's developing autonomous decision making abilities so that they can make fully autonomous decisions as an informed adult. However I have claimed there are other important reasons to think that disclosure of genetic risk is important. If we agree that respect for autonomy is not the only reason to disclose genetic information to children, then perhaps these same reasons also apply to PGT of children for adult onset diseases.

Establishing the importance of telling at-risk children about genetic conditions within the family is extremely important for the direction and focus of the second part of my discussion. Before I begin that discussion I need to highlight an assumption that cannot be left unchallenged. Disclosure and the subsequent successful incorporation of genetic knowledge into the child's self identity and the development of her autonomous capabilities assumes that she is told about the disease in a way she can make sense of. But it is also much more than that. Simply telling a child that a disease exists within the family is not sufficient if she is to benefit from such disclosure. Her family and social environment must support her, thus she needs to be surrounded by people who care about her, support her and her family, and are compassionate and sensitive to her needs.

The child who is told that HD is manifest within the family but who comes to associate this knowledge with fear and uncertainty, the erratic and frightening behaviour of parents and/or family members, or adults who are distant or who abandon the family when onset begins, will not be empowered by disclosure. In fact, I would suggest a child who is told information in such an environment may be duly traumatized and harmed by such knowledge. Conversely a child who is told for instance, that HD exists within the family and who sees extended family members caring for one another where support, both practical and moral is freely given, where the disease is considered a part

of one's life and the family are accepting and not fearful of it, is I believe, more likely to incorporate such knowledge positively into her self identity.

When the HGSA, and others claim that disclosure to children of genetic conditions within the family is important because being reared with such knowledge enables the child to make an informed choice about genetic testing (when a competent adult), they are saying something very important about the process of that disclosure. It is the content of and way in which disclosure takes place that is essential to the child's developing autonomous decision-making capacities.

II. Is predictive genetic testing the next step?

An obvious question then arises; if disclosure of disease risk is important because it enables the child to make a free choice about whether or not to be tested as an adult, and helps the child successfully incorporate such knowledge into their self-identity, why not test at-risk children for their genetic status? Whilst it is true that they will not be able to make a choice not to be tested as an adult, knowing their test result may benefit them by offering them important choices that would otherwise be denied to them if they did not know such genetic information. Second, as I argued in chapter two, the children would have grown up in an environment having always known and thus would have assimilated such knowledge into their self identity: the knowledge simply becomes a part of who they are.

Many children who are at risk for an inherited disease will not in fact carry the genetic mutation and thus are almost certainly free of ever developing the disease as an adult⁵⁷.

If tested and found not to carry the mutation they will grow up being able to make

⁵⁷ Even where an individual returns a favourable test result (no specific mutation has been identified), they will remain at the same level of risk as the general population. For instance, a person who does not carry either of the BRCA mutations still has a risk of developing breast and ovarian cancer. This is not the case for HD. A favourable test result means that individual will not develop HD.

different choices, for instance, about reproduction, than they may have made were they uncertain of their genetic status. As Robertson and Savulescu note, the child who knows the “*truth about herself*” will come to have different rather than fewer choices (Robertson & Savulescu, 2001 p 41). These include choices about her career, financial planning and end of life decision making (Ibid), (Savulescu, 2001). Furthermore, the parents of children (who are known not to carry the genetic mutation) presumably will not constantly look for ‘signs’ or symptoms that prior to testing they may have interpreted as symptoms of the disease. For them, a favourable test result will mean less anxiety and uncertainty.

Isn’t testing at-risk children for adult onset conditions known to exist within the family simply an extension of disclosure? Before answering this question, we must make it quite explicit what manner of disclosure is at issue. Whilst the guidelines recommend disclosing a disease risk to children, they do not detail how children are to be told, and when, or what kinds of information should be given to them. But it follows from their concern about informing children that disclosure must take a fairly ordered and planned path. As I have already argued, it is not sufficient to tell children once that a disease resides within the family and then leave them to find out on their own what this risk may mean for them. This will not nurture or facilitate their decision-making capabilities, nor does it respect them as individuals.

Disclosure surely requires that the child understands what they are being told, can make sense of the information (according to their age), are not fearful of it and are able to talk about it and ask questions whenever necessary. If this is what is intended by the process of disclosure then surely in such a supportive and open environment testing is a natural next step? For if the child is told about her risk in a supportive and caring environment

(which is surely what the guidelines are intending when they advocate disclosure), getting them tested could be understood as a part of the disclosure process. Presumably the guidelines would advise parents to seek professional help in how to disclose such information to their children and extended family members. This may also entail receiving specialist help and support from lay support groups (Skirton, 1998). Families that are dysfunctional and have trouble discussing personal information that impacts upon all members will no doubt have difficulty disclosing genetic information in an empowering way to young children. Adults who are pessimistic about their own genetic risk, who feel burdened by the disease, and who do not envisage a positive future for themselves or their children, may not communicate such risk positively or effectively with their children, if at all. Thus the testing of children for their risk status would not be advisable in such situations as it is not in the best interests of the child. It is also doubtful that disclosing a disease risk to children in such an environment is appropriate or in the child's best interests.

One may plausibly point out that there is a significant important difference between knowing you are at risk for a particular disease, and knowing for certain you have the gene that will one day develop into the disease. If you grow up knowing the risk, you can hope that you do not carry the mutation. One could reasonably claim that being tested and knowing for sure that you have the mutation may foreclose any hope by presenting the child with a doomed future – one that may mean premature senility and death. Being told that you are at risk but not being tested gives the child a certain amount of knowledge whilst retaining a degree of hope that one will not harbour the mutation.

There are three comments I want to make in response to this objection. First, it does not follow from the first claim (knowing only that you are at risk) that certainty (you have the gene for the disease) forecloses any further hope or indeed escalates one's sense of hopelessness. Knowing one's genetic inheritance may resolve uncertainty and allow the individual to plan their life still hopeful that a cure may be found, or that medical science may find a way of halting the progression of the disease or alleviating the symptoms that appear around onset. Hope does not exist solely in the desire not to be afflicted with the gene, hope comes in many forms: 'hope that I will not develop symptoms until I am much older', 'hope that my symptoms will be mild', or 'if I keep fit and healthy I hope I may be able to delay the onset'.

Second, a genetic test cannot indicate when onset will occur or how severe it will be. Individuals who have polycystic kidney disease may die elderly never having experienced symptoms that effect their lives, (PKD Foundation, 2004). Even within monogenic diseases, traditionally thought to be completely predictable on the basis of the presence or absence of a particular gene, those diseases such as cystic fibrosis and HD show wide variability (Cook, 1999). For polygenic or multifactorial diseases a positive test result does not necessarily mean that one will go on to develop the disease. Some individuals who carry the BRCA1 and BRCA2 genes may never develop breast cancer, and there are women who develop breast cancer who do not have the BRCA mutations (Collins et al., 2003). Furthermore, "*a positive genetic test may help patients by alerting them to the need for screening or preventive measures*" (Stephenson, 1999). The important point to make clear here is that predictive genetic tests do not offer genetic certainty about one's future health and mortality: such tests are not death sentences and neither are they analogous to crystal ball gazing. Rather they provide the individual with additional risk information that may be important for how they live their

lives. It is misleading to suggest and imply that genetic information alone can determine with precision if one will develop a disease, the severity of the disease and when onset is likely to occur because we simply do not have such accurate information.

Finally, although there are difficulties in extrapolating to children conclusions reached from studies involving adults (who are at risk for genetic conditions), we can make some useful observations⁵⁸. A review of the Huntington's literature by Meiser found that "*although risk factors for psychological sequelae have been identified, few adverse events have been described and no obvious contraindications for testing people at risk have been identified*" (Meiser & Dunn, 2000 p 2). This has also been confirmed by other commentators within the literature; (Decruyenaere et al., 1996), (Wiggins et al., 1992), (Lerman, Croyle, Tercyak, & Hamann, 2002), (Almqvist et al., 1999), (Broadstock et al., 2000; Bunday, 1997). The concern that HD gene-positive individuals faced an increased suicide risk has "*proved to be a rare event*" (Myers, 2004 p 258). Of course it must be remembered that the adults who choose to undergo testing have self selected and presumably feel confident enough in their ability to cope with the outcome, be it a negative or positive test result⁵⁹. Within the Huntington's literature there is evidence to suggest that those who undergo genetic testing do not lose hope; that in fact, knowing one carries the gene for the disease delivers many benefits to individuals. Even though most late onset diseases cannot be treated or their progression halted, knowing one has the genetic mutation may allow individuals greater control over the rest of their life's plans. For instance, even though an individual knows they

⁵⁸ It is interesting to note that whilst caution should be employed in how we interpret conclusions of adult studies in relation to how we understand children, one of the main arguments given not to test children for adult onset diseases is that adults at risk of HD generally decline to be tested (only between 12-15% of at-risk adults request testing). The inference made is that if at-risk adults decline to be tested, then surely we ought not to test children for once they become autonomous adults they too, may not want to be tested.

⁵⁹ I would like to thank Dr Angus Clarke for alerting me to this important point.

are likely to develop a disease within a certain number of years, such knowledge may give them greater impetus to achieve personal success and achievement in other areas of their life (for example, career, family, travel, and educational goals).

Conclusion

Telling children that a genetic condition resides within the family and that they are at risk of developing it as an adult is desirable for a number of important reasons: being told allows children to incorporate such knowledge into their self-identity, it respects the child's interest in not remaining voiceless until the age of majority, and it allows children to begin to make plans and set goals knowing what they do about their genetic inheritance. The international genetic service provider guidelines claim that disclosure enables children to grow up being able to make a free choice about genetic testing when a competent adult. What is being claimed here is that children, reared with such knowledge, are enabled in their developing autonomous capabilities to make informed and free decisions (as adults) by being supported and encouraged to understand what such knowledge may mean for them.

However I have argued that such a process of disclosure may not necessarily exclude PGT of children for adult onset diseases. Being genetically tested and reared with the resulting knowledge may give the child time to adjust to the information and provides her with a range of important choices she may otherwise not have. Rather than having to confront whether or not to be tested as an adult and face the uncertainty and fear that may accompany such a choice, already knowing one's genetic inheritance gives the child different important choices to make as an adult. I have claimed that in some families testing children for adult onset diseases may be seen as an extension of the disclosure process, and thus is in the child's best interests. The reasons given to defend

disclosure to children of genetic conditions within the family are also important reasons to cautiously defend predictive genetic testing of children for adult onset diseases.

Conclusion

Children are the central focus throughout this thesis. As important members of the moral community who possess unique moral status because of certain features only they (as a group) possess, I claimed that moral agents have a number of demanding obligations towards children: obligations we have to no other group in quite the same way. This is because children have fundamental needs, are vulnerable in a variety of relevantly important ways, are the future, and are ours. From the discussion in section one, it was clear that we are obliged to fulfil two significant obligations in relation to children: we have an obligation to facilitate and enable their developing autonomy and an obligation to protect them from serious harm. These conclusions provide a framework for thinking about how we ought to respond to requests to genetically test children for adult onset diseases.

Currently all genetic service provider guidelines and professional genetic societies recommend that children not be tested for those diseases where a direct medical intervention will not benefit children in the event a genetic mutation is identified. Wanting a medical benefit for children who are found to carry a genetic mutation is perfectly understandable. After all, if we could offer children or indeed any at-risk individual a cure for their disease, or amelioration of the symptoms at onset, or halt its progression, PGT may not be contentious or ethically problematic. This is because the medical benefits to individuals would be clear and direct.

However lack of medical benefit (to the child) is not the only consideration the various professional bodies argue ought to be taken into account. It is claimed that children who are genetically tested for adult onset diseases may be seriously harmed by the knowledge that results from a predictive genetic test. These harms include; the violation of children's future autonomy (namely their right not to know as an adult), discrimination and stigmatisation both within and outside the context of the family, and serious psychological harms. As we are obliged to protect children from serious harm and to enable rather than violate their developing autonomous decision-making capabilities, we must take seriously these claims of harm in relation to PGT.

Even when a medical benefit is not available though, it is reasonable to question and critically reflect on whether the information gained from a predictive genetic test offers children (and others) different kinds of important (non-medical) benefits. Or to put it another way, whilst we must address the question of serious harm, we must also take into account what harms may result if at-risk children are not tested for diseases that onset in adulthood.

In the discussion in section two I examined three serious harms alleged to occur if children were genetically tested for adult onset diseases: violation of their future autonomy as adults, adverse genetic discrimination in life insurance, and the psychological harms that may result from the knowledge a predictive genetic test would reveal about an individual, her future, and her family.

Violation of future autonomy stands centrally as a reason not to test children and forms current prohibitive testing policy. If children were to be tested before they could give their informed consent to such testing, when they became capable of self determination (as adults), the right not to know would have been forever denied to them. However I

argued that many of the decisions parents make in respect of their children prevent them later making a decision not to know. For instance, it is now considered correct to tell children about their biological origins so that children grow up knowing the truth about where they came from. We do not believe it appropriate to keep such information a secret from children and then ask them at eighteen whether or not they would like to know it. This information is important in the development of the child's self identity and assists them in understanding and learning about their place in the world; who they are connected to, what such knowledge will mean for their future and the plans they intend to make knowing what they do about themselves. Having children tested and disclosing the information to them in a way they can understand and make sense of, may in fact facilitate and nurture their developing autonomy rather than violate it.

If respect for personal autonomy grounds the right to know information (about oneself), does it also ground the right not to know personal information? In other words, can both the right to know and the right not to know be defended in the name of autonomy? I claimed one cannot defend a right not to know (the right to remain in ignorance) in autonomy's name. Central to the notion of personal autonomy is an individual's ability to reflect critically on what one needs, wants and desires for oneself. Such a capacity requires that a person makes deliberative choices free from coercion, and is accountable for the consequences of one's actions and behaviours. In order to make autonomous decisions, an individual requires information that is relevant and pertinent to one's life and the goals and desires one has initiated. We are responsible for our own lives and as such have an obligation to be informed. Such an understanding of autonomy is demanding and justifies our right to know. When information is denied to us, or is unavailable or too complex to understand, we cannot make autonomous choices. Thus we cannot demand a right not to know in the name of autonomy because autonomy

demands that we exercise our informed capacity to reason and this surely entails the pursuit of genetic information not the rejection of it.

I concluded that the argument not to genetically test children for adult onset diseases on the grounds that testing would violate the child's future autonomous right not to know genetic information does not stand up to critical and reasoned examination.

Furthermore one cannot defend a right not to know in the name of autonomy. Testing some children may facilitate and enable their developing autonomous decision-making abilities.

What about the argument that if we test children for these diseases they will face invidious discrimination in the context of life insurance? Life insurance companies require relevant information about an individual to estimate their probable risk of making a claim in the future. Thus they ask questions about known familial diseases, lifestyle activities and risky pursuits that one may be involved in. Genetic information supposedly offers underwriters a more accurate way of assessing that risk, and so it is argued such testing will result in individuals being denied insurance altogether, or of cover being prohibitively expensive if they have tested positive for a genetic mutation. However most genetic information does not and will not present insurance underwriters with the kind of accuracy and specificity it is alleged to reveal about an individual's life expectancy. Furthermore those individuals who are identified as being at low risk may decline taking out life insurance cover, or demand a reduction on their premiums. I suggested that insurance companies should be wary of overestimating the predictive value of genetic testing. For most people, genetic test result information will not provide underwriters with a more accurate way of determining risk, thus I suggest fears of adverse discrimination are not warranted, neither should we resist genetic testing.

On the other hand, PGT for adult onset diseases does offer more accurate information (although as I have noted, it cannot determine when a disease will onset, how severe the progression will be or when the individual will die); namely that the individual will develop the disease in adulthood unless they die of something else beforehand.

Nevertheless the numbers of individuals who carry genetic mutations for adult onset diseases are small and continually decreasing as individuals use reproductive technologies to avoid bringing children into the world who are affected by these diseases. As a morally decent society ought to support those who are not to blame for their disability or risk of premature death, a limited amount of life insurance cover could be extended to those individuals who have tested positive for these diseases. I conclude that if children are tested for adult onset diseases and found to be affected, financial security (for their dependents) is not only viable but reasonable to expect in the circumstances.

I addressed the concern that children may be psychologically harmed by the burden genetic knowledge may bring, especially the knowledge that a child carries a genetic mutation. As moral agents we have an obligation to protect children from serious harm and this includes psychological harm. These harms are particularly significant because not only may they seriously harm children now, but they may continue to adversely effect the adult the child will become. However it is unclear that PGT of children will result in the kinds of psychological harms that are alleged to occur. I critically considered three such harms: vulnerable child syndrome, limited horizons and damage to the child's self esteem. Parents ultimately lie at the heart of requests to test children. They are the ones who are primarily responsible for nurturing their child's self esteem, perceiving their children as being especially vulnerable, and responsible for the allocation of resources within the family. As most parents have their children's interests

at heart and want what is best for their children, if they are properly informed about the progression of the disease, the (likely) consequences of PGT, and receive professional support, such testing may not result in the putative psychological harms alleged to occur.

Finally I reflected on why it is important to tell children they are at-risk for inherited diseases. Respecting children as individuals who have an interest in developing into autonomous individuals means recognising that they have an interest in being told pertinent information that is relevant to them both now and in the future. This is why we now consider it crucial that children are told they were adopted, or that their conception involved the donation of germinal material, or that they are at-risk for an inherited disease. To disclose such information to children respects their developing autonomy, but it also recognises that children are not well served by being kept in the dark. However the process of disclosure and subsequent successful incorporation of genetic knowledge, assumes the child is told about the disease in a way she can understand. It also requires that her family and social environment supports her and are sensitive and compassionate to her needs. I argued that a process of disclosure may not necessarily exclude PGT of children for adult onset diseases. The reasons given to defend disclosure to children of genetic conditions within the family are also important reasons to cautiously defend PGT of children for adult onset diseases.

Disclosure to children about their genetic inheritance conveys to them in a very powerful way, that disease is a part of our lives and that our genetic makeup does not solely define who we are. Knowing we carry a particular genetic mutation does not make us any less worthy or valuable as a human being. In fact knowing from a young age that one carries the gene(s) responsible for a disease that will onset in the future

may give individuals and their families a deeper appreciation of what gives life meaning and value. Children generally live in families and communities where they are nurtured and supported by people who love and care for them. In some families genetically testing them for an adult onset disease may confer direct benefits to them; benefits they may be deprived of if parental and children's requests for PGT are denied.

I do not and have not advocated PGT for all children who are at-risk for an adult onset disease. Such a position would be foolhardy and irresponsible because many individuals and families struggle with the implications of living with an adult onset disease and the knowledge they receive from a genetic test may not benefit their lives in any positive way. For some individuals continued uncertainty may be preferable to knowing they carry an inherited disease. However a family that acknowledges and accepts the presence of a genetic disease that onsets in adulthood, who support one another, believe the disease is a part of who they are, and who believes the child will benefit from being tested, may request PGT for their children in the sincere belief that such knowledge will benefit the children's lives in an empowering way. As parents generally have the best interests of their children at heart, we cannot assume (as current PGT policy infers) that all parents who request testing for their children are mistaken in what those best interests may be. Not genetically testing some children may deny them important benefits.

At the heart of the matter are children. Our obligations to them, in respect of their unique moral status require that we take seriously the ethical implications of PGT. In conclusion, I claim that the answer to the question, 'should we test currently healthy, asymptomatic at-risk children for disease that will not develop until they are adults?' may be cautious support of testing in qualified circumstances.

References

- Aber, J., Bennett, N., Conley, D., & Li, J. (1997). The effects of poverty on child health and development. *Annu Rev Publ Health, 18*, 463-483.
- Alderson, P. (1998). Talking to children - and talking with them. In A. Clarke (Ed.), *The genetic testing of children* (pp. 27-36). Oxford, Washington DC: Bios Scientific Publishers.
- Allen, E., Manuel, J., Legault, C., Naughton, M., Pivor, C., & O'Shea, T. (2004). Perception of child vulnerability among mothers of former premature infants. *Pediatrics, 113*(2), 267-273.
- Almqvist, E., Bloch, M., Brinkman, R., Craufurd, D., & Hayden, M. (1999). A worldwide assessment of the frequency of suicide, suicide attempts, or psychiatric hospitalization after predictive testing for Huntington disease. *Am J Hum Genet, 64*, 1293-1304.
- American Academy of Pediatrics. (2001). *Ethical issues with genetic testing in pediatrics*. Retrieved August 26, 2002, from <http://www.aap.org/policy/re9924.html>
- American Society of Human Genetics Social Issues Committee, & American College of Medical Genetics Social, E., Legal Issues Committee. (2000). Genetic testing in adoption. *Am J Hum Genet, 66*, 761-767.
- Archard, D. (1993). *Children, rights and childhood*. London and New York: Routledge.
- Archard, D. (2003a). Children. In H. LaFollette (Ed.), *The Oxford handbook of practical ethics* (pp. 772). New York: Oxford University Press.
- Archard, D. (2003b). *Children, family and the state*. Hampshire, England and Burlington, USA: Ashgate.
- Archard, D., & Macleod, C. (Eds.). (2002). *The moral and political status of children*: Oxford University Press.
- Armstrong, K., Weber, B., FitzGerald, G., Hershey, J., Pauly, M., Lemaire, J., et al. (2003). Life insurance and breast cancer risk assessment: adverse selection, genetic testing decisions, and discrimination. *Am J Med Genet, 120A*, 359-364.
- Arneil, B. (2002). Becoming versus being: A critical analysis of the child in liberal theory. In D. Archard & C. Macleod (Eds.), *The moral and political status of children* (pp. 70-94). Oxford: Oxford University Press.

- Arpaly, N. (2003). *Unprincipled virtue: an inquiry into moral agency*. Oxford, UK: Oxford University Press.
- ASHG/ACMG, American Society of Human Genetics Board of Directors, & Directors, T. A. C. o. M. G. B. o. (1995). ASHG/ACMG Report. Points to consider: ethical, legal and psychosocial implications of genetic testing in children and adolescents. *Am J Hum Genet*, 57, 1233-1241.
- Ball, D., Tyler, A., & Harper, P. (1994). Predictive testing of adults and children. Lessons from Huntington's disease. In A. Clarke (Ed.), *Genetic Counselling: Practice and principles* (pp. 63-94). London, New York: Routledge.
- Barber, N. (2000). *Why parents matter. Parental investment and child outcomes*. Connecticut. London: Bergin & Garvey.
- Basu, S. (2004). Genetic privacy: resolving the conflict between the donor and child. *Curr Sci*, 86(19), 1363-1365.
- BBC. (2002). *Call to end sperm donor anonymity*. Retrieved August 2004, May 14, 2002, from <http://news.bbc.co.uk/1/hi/health/1986683.stm>
- Bearison, D., J. (1991). *"They never want to tell you". Children talk about cancer*. London: Harvard University Press.
- Beauchamp, T., & Childress, J. (1994). *Principles of biomedical ethics* (Fourth ed.). New York: Oxford University Press.
- Beckwith, J., & Alper, J. (1998). Reconsidering genetic antidiscrimination legislation. *J Law Med Ethics*, 26(3), 205-210.
- Beitchman, J. H., Zucker, K. J., Hood, J. E., DaCosta, G. A., Akman, D., & Cassavia, E. (1992). A review of the long-term effects of child sexual abuse. *Child Abuse and Neglect*, 16, 101-118.
- Bek, K., Tomaç, N., Delibas, A., Tuna, F., Teziç, H., & Sungur, M. (1999). The effect of passive smoking on pulmonary function during childhood. *Postgrad Med J*, 75, 339-341.
- Benporath, S. R. (2003). Autonomy and vulnerability: on just relations between adults and children. *Journal of Philosophy and Education*, 37(1), 127-145.
- Bergman, A., & Wiesner, L. (1976). Relationship of passive cigarette smoking to sudden infant death syndrome. *Pediatrics*, 58, 665-668.
- Bigner, J. J. (1989). *Parent-child relations. An introduction to parenting*. New York: Macmillan Publishing Company.
- Billings, P., Kohn, M., M de Cuevas, Beckwith, J., Alper, J., & Natowicz, M. (1992). Discrimination as a consequence of genetic testing. *Am J Hum Genet*, 50, 476-482.

- Bloch, M., & Hayden, M. (1990). Opinion: Predictive testing for Huntington disease in childhood: challenges and implications. *Am J Hum Genet*, 46, 1-4.
- Blustein, J. (1982). *Parents and children: The ethics of the family*. New York, Oxford: Oxford University Press.
- Bonn, D. (2000). Genetic testing and insurance: fears unfounded. *Lancet*, 255(9214), 15-26.
- Bowman, S., Gortmaker, S., Ebbeling, C., Pereira, M., & Ludwig, D. (2004). Effects of fast-food consumption on energy intake and diet quality among children in a national household survey. *Pediatrics*, 113(1), 112-118.
- Boyce, W. (1992). The vulnerable child: new evidence, new approaches. *Adv Pediat*, 39, 1-33.
- Brennan, S. (2002). Children's choices or children's interests: which do their rights protect? In D. Archard & C. Macleod (Eds.), *The moral and political status of children* (pp. 53-69). Oxford, New York: Oxford University Press.
- Brennan, S., & Noggle, R. (1997). The moral status of children: Children's rights, parents' rights and family justice. *Soc Theor Pract*, 23(1), 1-26.
- Broadstock, M., Michie, S., & Marteau, T. (2000). Psychological consequences of predictive genetic testing: a systematic review. *Eur J Hum Genet*, 8, 731-738.
- Bunday, S. (1997). Few psychological consequences of presymptomatic testing for Huntington disease. *Lancet*, 349(9044), 4.
- Burnside, J. (1997). *Ethical quandaries in genetic testing*. Retrieved July 2004, February 1997, from <http://www.texmed.org/ata/tos/ets/texmedfeb97ethgt.asp>
- Callan, E. (2002). Autonomy, child-rearing, and good lives. In D. Archard & C. Macleod (Eds.), *The moral and political status of children* (pp. 118-141). Oxford: Oxford University Press.
- Campbell, E., & Ross, L. F. (2003a). Parental attitudes regarding newborn screening of PKU and DMD. *Am J Med Genet*, 120A, 209-214.
- Campbell, E., & Ross, L. F. (2003b). Professional and personal attitudes about access and confidentiality in the genetic testing of children: a pilot study. *Genet Test*, 7(2), 123-130.
- Canadian Paediatric Society. (2003). Guidelines for genetic testing of healthy children. *Paediatr Child H*, 8(1), 42-45.
- Casey, D. (1997). *What can the new gene tests tell us?* Retrieved 6 August, 2004, from http://www.ornl.gov/sci/techresources/Human_Genome/publicat/judges/judge.html
- CEJA. (1995). *Report 4 - A-95 'Testing children for genetic status'*. Retrieved August 30, 2004, from <http://www.ama-assn.org/ama/pub/category/2498.html>

- Child Poverty Action Group. (2003). *Our children: the priority for policy. 2nd Edition*. Auckland: Child Poverty Action Group (Inc).
- Child Poverty Action Group Inc. (2005). *Child poverty statistics*.
- Clafflin, C. J., & Barbarin, O. A. (1991). Does "telling" less protect more? Relationships among age, information disclosure, and what children with cancer see and feel. *J Pediatr Psychol, 16*(2), 169-191.
- Clarke, A. (Ed.). (1998). *The genetic testing of children*. Oxford, Washington DC: Bios Scientific Publishers.
- Clarke, A., Fleming, D., Kerzin-Storarr, L., Middleton-Price, H., Montgomery, J., Payne, H., et al. (1994). The genetic testing of children. Working party of the Clinical Genetics Society (UK). *J Med Genet, 31*, 785-797.
- Clarke, A., & Flinter, F. (1996). The genetic testing of children: a clinical perspective. In T. Marteau & M. Richards (Eds.), *The troubled helix: social and psychological implications of the new human genetics*. Cambridge: Cambridge University Press.
- Cohen, C. (1998). Wrestling with the future: should we test children for adult-onset genetic conditions? *Kennedy Inst Ethic J, 8*(2), 111-130.
- Collins, F., Weiss, L., & Hudson, K. (2003). Heredity and humanity: Have no fear, genes aren't everything. In B. Steinbock, J. Arras & A. London (Eds.), *Ethical issues in modern medicine* (Vol. 6th, pp. 553-557): McGraw Hill.
- Committee on Environmental Health. (1997). Environmental tobacco smoke: a hazard to children. *Pediatrics, 99*, 639-642.
- Cook, E. D. (1999). Genetics and the British insurance industry. *J Med Ethics, 25*, 157.
- Coopersmith, S. (1967). *The antecedents of self-esteem*. San Francisco and London: W H Freeman and Company.
- Covell, K., & Howe, R. (1998). A policy of parent licensing. *Options Politiques, 32-35*.
- Cystic Fibrosis Foundation. (2004, May 2004). *What is Cystic Fibrosis?* Retrieved October 2004, 2004, from http://www.cff.org/about_cf/what_is_cf/
- Daniels, S. (2006). The consequences of childhood overweight and obesity. *The Future of Children, 16*(1), 47-67.
- Davies, E., Wood, B., & Wilson, D. (2003). Enhancing children's rights to protection from violence and neglect in Aotearoa New Zealand. *Childrenz Issues, 7*(1), 17-24.
- Davis, D. S. (2001). *Genetic dilemmas. Reproductive technology, parental choices, and children's futures*. London: Routledge.

- de Vaus, D. (1994). *Letting go. Relationships between adults and their parents*. Oxford, Auckland, New York: Oxford University Press.
- Decruyenaere, M., Evers-Kiebooms, G., Boogaerts, A., Cassiman, J., Cloostermans, T., Demyttenaere, K., et al. (1996). Prediction of psychological functioning one year after the predictive test for Huntington's disease and impact of the test result on reproductive decision making. *J Med Genet*, 33, 737-743.
- Department of Child, Y. a. F. S. (2005). *Annual report*. Wellington: Department of Child, Youth and Family Services.
- Dickenson, D. (1999). Can children and young people consent to be tested for adult onset genetic disorders? *BMJ*, 318, 1063-1066.
- Duncan, G. J., & Brooks-Gunn, J. (2000). Family poverty, welfare reform, and child development. *Child Dev*, 71(1).
- Duncan, G. J., Brooks-Gunn, J., Young, W. J., & Smith, J. R. (1998). How much does childhood poverty affect the life chances of children? *Am Sociol Rev*, 63(3), 406-423.
- Duncan, R. E. (2004). Predictive genetic testing in young people: When is it appropriate? *J Paediatr Child H*, 40, 593-595.
- Dworkin, G. (1988). *The theory and practice of autonomy*. Cambridge: Cambridge University Press.
- Eagle, L., de Bruin, L., & Bulmer, S. (2002). *The children-nutrition-marketing ethics conundrum: identifying the issues* (No. Working Paper 02.16 rev): Massey University (Auckland).
- Edwards, M., & Davis, H. (1997). *Counselling children with chronic medical conditions*. London: BPS Books.
- Eiser, C. (1993). *Growing up with a chronic disease. The impact on children and their families*. London: Jessica Kingsley Publishers Ltd.
- Elger, B. S., & Harding, T. W. (2006). Should children and adolescents be tested for Huntington's disease? Attitudes of future lawyers and physicians in Switzerland. *Bioethics*, 20(3), 158-167.
- Everett, M. (2004). Can you keep a (genetic) secret? The genetic privacy movement. *J Genet Counseling*, 13(4), 273-291.
- Fanos, J. (1997). Developmental tasks of childhood and adolescence: implications for genetic testing. *Am J Med Genet*, 71, 22-28.
- Freedman, D., Kettel-Khan, L., Dietz, W., Srinivasan, S., & Berenson, G. (2001). Relationship of childhood obesity to coronary heart disease risk factors in adulthood: the Bogalusa Heart Study. *Pediatrics*, 108(3), 712-718.

- Freeman, M. (1997). *The moral status of children. essays on the rights of the child*: Martinus Nijhoff Publishers.
- Friedman-Ross, L., & Moon, M. (2000). Ethical issues in genetic testing of children. *Arch Pediat Adol Med*, 154(9), 873-879.
- Fryer, A. (2000). Inappropriate genetic testing of children. *Arch Dis Child*, 83, 283-285.
- Gaylin, W., & Jennings, B. (2003). *The perversion of autonomy. Coercion and constraint in a liberal society*. Washington, D.C.: Georgetown University Press.
- Gaylin, W., & Macklin, R. (Eds.). (1982). *Who speaks for the child? The problems of proxy consent*. New York: Plenum Press.
- Genetic Interest Group. (1995). GIG responses to the UK Clinical Genetics Society report "The genetic testing of children". *J Med Genet*, 32, 490-494.
- Genewatch UK. (2001). *Genetic testing in insurance and employment: A new form of discrimination* (No. 15).
- Gibbons, M. (2001). Psychosocial aspects of serious illness in childhood and adolescence. In A. Armstrong-Dailey & S. Zarbock (Eds.), *Hospice care for children* (2 ed.): Oxford University Press.
- Goodin, R. (1985). *Protecting the vulnerable. A reanalysis of our social responsibilities*. Chicago, London: The University of Chicago Press.
- Green, M., & Solnit, A. (1964). Reaction to the threatened loss of a child: a vulnerable child syndrome. *Pediatrics*, 53-66.
- Gregor, M. (Ed.). (1996). *Immanuel Kant. The metaphysics of morals*. Cambridge, New York: Cambridge University Press.
- Griffin, J. (2002). Do children have rights? In D. Archard & C. Macleod (Eds.), *The moral and political status of children* (pp. 296). Oxford: Oxford University Press.
- Griffith, K. (1991). *The right to know who you are. Reform of adoption law with honesty, openness and integrity*.: KW Kimbell.
- Hall, M. A., & Rich, S. S. (2000). Patients' fear of genetic discrimination by health insurers: the impact of legal protections. *Genet Med*, 2(4), 214-221.
- Harper, P. S. (1993). Insurance and genetic testing. *Lancet*, 341(8839), 224-228.
- Harper, P. S., & Clarke, A. (1990). Should we test children for "adult" genetic diseases? *Lancet*, 335, 1205-1206.
- Harris, J. (1989). *The value of life*. London: Routledge.
- Harris, J., & Keywood, K. (2001). Ignorance, information and autonomy. *Theor Med*, 22, 415-436.

- Haworth, L. (1986). *Autonomy. An essay in philosophical psychology and ethics*. New Haven and London: Yale University Press.
- Hoffmann, D., & Wulfsberg, E. (1995). Testing children for genetic predispositions: is it in their best interest? *J Law Med Ethics*, 23, 331-344.
- Holtzman, N., & Marteau, T. (2000). Will genetics revolutionize medicine? *New Engl J Med*, 343(2), 141-144.
- Honderich, T. (Ed.). (1995). *The Oxford companion to philosophy*. Oxford: Oxford University Press.
- Hubbard, R., & Elijah, W. (1993). *Exploding the gene myth. How genetic information is produced and manipulated by scientists, physicians, employers, insurance companies, educators, and law enforcers*. Boston: Beacon Press.
- Human Genetics Society of Australasia. (2003). *Predictive testing in children and adolescents*. Retrieved August 25, 2004, from <http://www.hgsa.com.au/policy/ptca.html>
- Human Genome Project Information. (2004, July 9, 2004). *Gene testing: For what diseases are gene tests available?* Retrieved October 19, 2004, 2004, from http://www.ornl.gov/sci/techresources/Human_Genome/medicine/genetest.shtml
- Hunter, M., Salter-Ling, N., & Glover, L. (2000). Donor insemination: Telling children about their origins. *Child Psych Psychiat Rev*, 5(4), 157-163.
- Huntington's Disease Society of America. (1994). *Guidelines for genetic testing for Huntington's disease*, from <http://www.hdfoundation.org/testread/hdsatest.htm>
- International Huntington Association. (2004, March 1, 2004). *Guidelines for the molecular genetics predictive test in Huntington's disease*. Retrieved October 19, 2004, 2004, from <http://www.huntington-assoc.com/>
- Investment Savings and Insurance Association of NZ Inc. (2000). *ISI Underwriting guide*.
- Investment Savings and Insurance Association of NZ Inc. (2004). *ISI Policy on genetic testing*: Investment Savings and Insurance Association of NZ, Inc.
- Janssen, I., Craig, W., Boyce, W., & Pickett, W. (2004). Associations between overweight and obesity with bullying behaviors in school-aged children. *Pediatrics*, 113(5), 1187-1194.
- Jarvinen, O., & Kaariainen, H. (1998). A retrospective study of genetic carrier testing in childhood. In A. J. Clarke (Ed.), *The genetic testing of children* (pp. 91-96). Oxford, Washington DC: Bios Scientific Publishers.
- Karpel, M. (1980). Family secrets. *Family Process*, 19, 295-306.

- Keefer, B., & Schooler, J. E. (2000). *Telling the truth to your adopted or foster child. Making sense of the past*. London: Bergin and Garvey.
- Kemper, K., Forsyth, B., & McCarthy, P. (1989). Jaundice, terminating breast-feeding, and the vulnerable child. *Pediatrics*, *84*(5), 773-777.
- Kent, A. (2003). Consent and confidentiality in genetics: whose information is it anyway? *J Med Ethics*, *29*, 16-18.
- Knoppers, B., & Joly, Y. (2004). Physicians, genetics and life insurance. *CMAJ*, *170*(9), 1421-1423.
- Koocher, G. (1986). Psychosocial issues during the acute treatment of pediatric cancer. *Cancer*, *58*, 468-472.
- Korenman, S., Miller, J., & Sjaastad, J. (1995). Long-term poverty and child development in the United States: results from the NLSY. *Children and Youth Services Review*, *17*(1/2), 127-155.
- Lafollette, H. (1980). Licensing parents. *Philos Public Aff*, *9*(2), 182-197.
- Lafollette, H., & May, L. (1996). "Suffer the little children", from <http://www.stpt.usf.edu/hhl/papers/suffer.htm>
- Landrigan, P. J., Claudio, L., Markowitz, S. B., Berkowitz, G. S., Brenner, B. L., Romero, H., et al. (1999). Pesticides and inner-city children: exposures, risks, and prevention. *Environmental Health Perspectives*, *107*(Supp 3).
- Lapham, E. V., Kozma, C., & Weiss, J. O. (1996). Genetic discrimination: perspectives of consumers. *Science*, *274*, 621-624.
- Launis, V. (2003). Solidarity, genetic discrimination, and insurance: a defense of weak genetic exceptionalism. *Soc Theor Pract*, *29*(1), 87-111.
- Lemmens, T. (2000). Selective justice, genetic discrimination, and insurance: should we single out genes in our laws? *McGill Law Journal*, *45*, 347-412.
- Lerman, C., Croyle, R., Tercyak, K., & Hamann, H. (2002). Genetic testing: psychological aspects and implications. *J Consul Clin Psychol*, *70*(3), 784-797.
- Lessick, M., & Faux, S. (1998). Implications of genetic testing of children and adolescents. *Holist Nurs Pract*, *12*(3), 38-46.
- Livingstone, B. (2000). Epidemiology of childhood obesity in Europe. *Eur J Pediatr*, *159* (Supp 1), S14-34.
- Lloyd, P. J., Anionwu, D. E., Ewing, P. K., Greene, L., Harper, P. P., McLaren, A., et al. (1993). *Nuffield Council on Bioethics: Genetic screening. Ethical issues*. London.

- Low, L., King, S., & Wilkie, T. (1998). Genetic discrimination in life insurance: empirical evidence from a cross sectional survey of genetic support groups in the United Kingdom. *BMJ*, *317*(7173), 1632-1635.
- Lykken, D. (2000). The causes and costs of crime and a controversial cure. *J Pers*, *68*(3), 559-605.
- MacDonald, C., & Williams-Jones, B. (2002). Ethics and genetics: susceptibility testing in the workplace. *J Bus Ethics*, *35*, 235-241.
- Macklin, R. (1982). Return to the best interests of the child. In W. Gaylin & R. Macklin (Eds.), *Who speaks for the child: The problems of proxy consent* (pp. 265-301). New York, London: Plenum Press.
- Malpas, P. J. (2005a). Predictive genetic testing in children and respect for autonomy. *Int J Child Rights*, *13*, 251-263.
- Malpas, P. J. (2005b). The right to remain in ignorance about genetic information - can such a right be defended in the name of autonomy? *NZMJ*, *118*(1220), 1611-1619.
- Malpas, P. J. (2006). Telling at-risk, asymptomatic children an adult onset disease exists within the family but refusing to test them for it. Why not test? *JME*, *32*(11), 639-642.
- Matloff, E., Shappell, H., Brierley, K., Bernhardt, B., McKinnon, W., & Peshkin, B. (2000). What Would You Do? Specialists' Perspectives on Cancer Genetic Testing, Prophylactic Surgery, and Insurance Discrimination. *J Clin Oncol*, *18*(12), 2484-2492.
- May, T. (1998). *Autonomy, authority and moral responsibility* (Vol. 33). London: Kluwer Academic Publishers.
- McCloskey, L. A., & Becker, K. B. (2002). Attention and conduct problems in children exposed to family violence. *Am J Orthopsychiatry*, *72*(1), 83-91.
- McCloskey, L. A., Figueredo, A. J., & Koss, M. P. (1995). The effects of systemic family violence on children's mental health. *Child Development*, *66*(5), 1239-1261.
- McConkey, E. H. (2004). *How the human genome works*. Boston: Jones and Bartlett Publishers.
- McEwen, J., McCarty, K., & Reilly, P. (1993). A survey of medical directors of life insurance companies concerning use of genetic information. *Am J Hum Genet*, *53*, 33-45.
- McIntire, R. (2004). Parenthood training or mandatory birth control: Take your choice. In P. Tittle (Ed.), *Should parents be licensed? Debating the issues* (pp. 90-97). New York: Prometheus Books.

- McLeod, J., & Shanahan, M. (1993). Poverty, parenting, and children's mental health. *Am Soc Rev*, 58(3), 351-366.
- Meiser, B., & Dunn, S. (2000). Psychological impact of genetic testing for Huntington's disease: an update of the literature. *J Neurol Neurosurg Psychiatry*, 69, 574-578.
- Michie, S. (1996). Predictive genetic testing in children: paternalism or empiricism? In T. Marteau & M. Richards (Eds.), *The troubled helix: social and psychological implications of the new genetics* (pp. 177-183). Cambridge: Cambridge University Press.
- Michie, S., & Marteau, T. (1996). Predictive genetic testing in children: the need for psychological research. *Brit J Health Psych*, 1, 3-14.
- Mill, J. S. (1974). *On liberty*: Penguin Books Ltd.
- Mills, C. (2001). Workplace wars: how much should I be required to meet the needs of your children? *Philos Public Policy Q*, 21(1), 15-20.
- Mincey, B. A. (2003). Genetics and the management of women at high risk for breast cancer. *Oncologist*, 8(5), 466-473.
- Ministry of Economic Development. (2005). *Appendix 3: Existing insurance regulatory regime*: Ministry of Economic Development.
- Ministry of Health. (2004). *Newborn baby metabolic screening*. Retrieved October 19, 2004, from [http://www.moh.govt.nz/moh.nsf/0/541c9f741b2d3f60cc256c0b0078eed5/\\$FILE/wellchild-newborn-baby-metabolic-screening080802.pdf](http://www.moh.govt.nz/moh.nsf/0/541c9f741b2d3f60cc256c0b0078eed5/$FILE/wellchild-newborn-baby-metabolic-screening080802.pdf)
- Ministry of Health. (2005). *Monitoring health inequality through neighbourhood life expectancy: public health intelligence occasional bulletin no. 28* (No. 28). Wellington: Ministry of Health.
- Ministry of Social Development. (2002). *New Zealand's agenda for children - making life better for children*. Wellington: Ministry of Social Development,.
- Ministry of Social Development. (2005). *The social report 2005: Indicators of social wellbeing in New Zealand*. Wellington.
- Ministry of Social Development, Fergusson, D., Horwood, J., Ridder, E., & Grant, H. (2005). *Early start. Evaluation report*. Christchurch: Ministry of Social Development.
- Mitchell, K. J., Finkelhor, D., & Wolak, J. (2003). The exposure of youth to unwanted sexual material on the internet. A national survey of risk, impact and prevention. *Youth and Society*, 34(3), 330-358.
- Mitra, J., & Sulston, J. (2004). Genetics and life assurance: should we legislate? *Genomics Network*(1), 9-12.

- Morris, M., Tyler, A., & Harper, P. (1988). Adoption and genetic prediction for Huntington's disease. *Lancet*.
- Murray, T. H. (1996). *The worth of a child*. California: University California Press.
- Must, A., & Strauss, R. (1999). Risks and consequences of childhood and adolescent obesity. *Int J Obesity*, 23, (Supp 2):, S2-S11.
- Myers, R. (2004). Huntington's disease genetics. *NeuroRx*, 1, 255-262.
- Narveson, J. (1988). *The libertarian idea*. Philadelphia: Temple University Press.
- National Advisory on Health and Disability. (2003). *Molecular genetic testing in New Zealand*: National Health Committee.
- National Health and Medical Research Council. (2000). *Ethical aspects of human genetic testing: an information paper*. Canberra: NHMRC.
- National Society of Genetic Counselors. (2003). *Position statements: Prenatal and childhood testing for adult-onset disorders*. Retrieved 28 January, 2004, 2004, from <http://www.nsgc.org/about/position.asp>
- Natowicz, M., Alper, J., & Alper, J. (1992). Genetic discrimination and the law. *Am J Hum Genet*, 50, 465-475.
- New Zealand Health Strategy. (2001a). *DHB Toolkit: Interpersonal violence* (No. 1).
- New Zealand Health Strategy. (2001b). *DHB Toolkit: Obesity*. Retrieved February, 2005, from <http://www.newhealth.govt.nz/toolkits/obesity/Obesity0102.pdf>
- New Zealand Law Commission. (2004). *Life insurance* (No. 87). Wellington.
- Nowlan, W. (2002). A rational view of insurance and genetic discrimination. *Science*, 297, 195-196.
- Nozick, R. (1974). *Anarchy, state and utopia*: Basic Books.
- Nuttall, P. (1991). *Self-esteem and children*. Retrieved October, 2004, from <http://www.nncc.org/Guidance/self.esteem.html>
- Olds, D., & Kitzman, H. (1990). Can home visitation improve the health of women and children at environmental risk? *Pediatrics*, 86(1).
- Olshansky, S., Passaro, D., Hershow, R., Layden, J., Carnes, B., Brody, J., et al. (2005). A potential decline in life expectancy in the United States in the 21st century. *The New England Journal of Medicine*, 352(11), 1138-1145.
- O'Neill, M. (2005). *Genetic information, life insurance and social justice*. Retrieved 5 December, 2005, 2005, from <http://mora.rente.nhh.no/projects/EqualityExchange/Home/tabid/36/Default.aspx>

- O'Neill, O., & Ruddick, W. (Eds.). (1979). *Having children. Philosophical and legal reflections on parenthood*. New York: Oxford University Press.
- Osofsky, J. D. (2003). Prevalence of children's exposure to domestic violence and child maltreatment: implications for prevention and intervention. *Clinical Child and Family Psychology Review*, 6(3), 161-170.
- Otlowski, M. F., Taylor, S. D., & Barlow-Stewart, K. K. (2003). Genetic discrimination: too few data. *Eur J Hum Genet*, 11, 1-2.
- Partridge, E. (2005). *Why should I pay for someone else's education?* Retrieved 4 Jan, 2006, from <http://www.scoop.co.nz/stories/print.html?path=HL0504/S00052.htm>
- Pearce, M., Boergers, J., & Prinstein, M. (2002). Adolescent obesity, overt and relational peer victimization, and romantic relationships. *Obesity Research*, 10, 386-393.
- Pembrey, M. (1996). The new genetics: a user's guide. In T. Marteau & M. Richards (Eds.), *The troubled helix: social and psychological implications of the new human genetics* (pp. 63-81). Cambridge: Cambridge University Press.
- Perrin, E., West, P., & Culley, B. (1989). Is my child normal yet? Correlates of vulnerability. *Pediatrics*, 83(3), 355-363.
- Pierce, C., & vanDe Veer, D. (Eds.). (1995). *People, penguins, and plastic trees*: Wadsworth Publishing Company.
- PKD Foundation. (2004). *What are the symptoms of PKD?* Retrieved December 1, 2004, from <http://www.pkdcure.org/home.html>
- Privacy Commissioner. (2003). *"Guthrie tests"*. Retrieved June, 2005, 2005, from <http://www.privacy.org.nz/media/Guthrie%20final%20report.pdf>
- Rachels, J. (1997). *Can ethics provide answers? And other essays in moral philosophy*. Lanham, Boulder, New York, London: Rowan and Littlefield Publishers, Inc.
- Radetzki, M., Radetzki, M., & Juth, N. (Eds.). (2003). *Genes and insurance. Ethical, legal and economic issues*. UK: Cambridge University Press.
- Raithatha, N., & Smith, R. (2004). Disclosure of genetic tests for health insurance; Is it ethical not to? *Lancet*, 363, 395-396.
- Rawls, J. (1971). *A theory of justice* (Revised edition ed.). Oxford, New York: Oxford University Press.
- Regan, T. (2004). *Empty cages: facing the challenge of animal rights*: Rowman & Littlefield Publishers, Inc.
- Regan, T., & Singer, P. (Eds.). (1989). *Animal rights and human obligations* (2nd ed.). NJ: Englewood Cliffs, Prentice Hall.

- Reilly, J., & Dorosty, A. (1999). Epidemic of childhood obesity in UK children. *Lancet*, 354, 1874-1875.
- Reilly, J., Methven, E., McDowell, Z., Hacking, B., Alexander, D., Stewart, L., et al. (2003). Health consequences of obesity. *Arch Dis Child*, 88, 748-752.
- Risman, B. *The causes and consequences of children's poverty*. Retrieved 3rd September, 2005, from http://www.ces.ncsu.edu/depts/sociology/pub/qol/the_causes_and_consequenses_of_children_poverty.html
- Robertson, S., & Savulescu, J. (2001). Is there a case in favour of predictive genetic testing in young children? *Bioethics*, 15(1), 26-49.
- Rothenberg, K., & Terry, S. (2002). Before it's too late - addressing fear of genetic information. *Science*, 297, 196-197.
- Rothstein, M. (1998). Genetic privacy and confidentiality: why they are so hard to protect. *J Law Med Ethics*, 26(3), 198-204.
- Rovio, S., Kareholt, I., Helkala, E., Viitanen, M., Winblad, B., Tuomilehto, J., et al. (2005). Leisure-time physical activity at midlife and the risk of dementia and Alzheimer's disease. *Lancet Neurol*, 4, 705-711.
- Rubinsztein, D., Leggo, J., Coles, R., Almqvist, E., Biancalana, V., Cassiman, J., et al. (1996). Phenotypic characterization of individuals with 30-40 CAG repeats in the Huntington disease (HD) gene reveals HD cases with 36 repeats and apparently normal elderly individuals with 36-39 repeats. *Am J Hum Genet*, 59(1), 16-22.
- Sandler, D., Everson, R., Wilcox, A., & Browder, J. (1985). Cancer risk in adulthood from early life exposure to parents' smoking. *Am J Public Health*, 75, 487-492.
- Sankar, P. (2003). Genetic privacy. *Annu Rev Med*, 54, 393-407.
- Savulescu, J. (2001). Predictive genetic testing in children. *Med J Australia*, 175, 370-381.
- Schonberg, S. K., Anderson, S. J., Bays, J. A., & Duncan, P. (1998). The role of home-visitation programs in improving health outcomes for children and families. *Pediatrics*, 101(3), 486-489.
- Schooler, J. E., & Norris, B. L. (2002). *Journeys after adoption: Understanding lifelong issues*: Bergin and Garvey.
- Schweitzer, A. (1987). *The philosophy of civilization* (C. T. Campion, Trans.): Prometheus Books.
- Selvini, M. (1997). Family secrets: the case of the patient kept in the dark. *Contemp Fam Ther*, 19(3), 315-335.

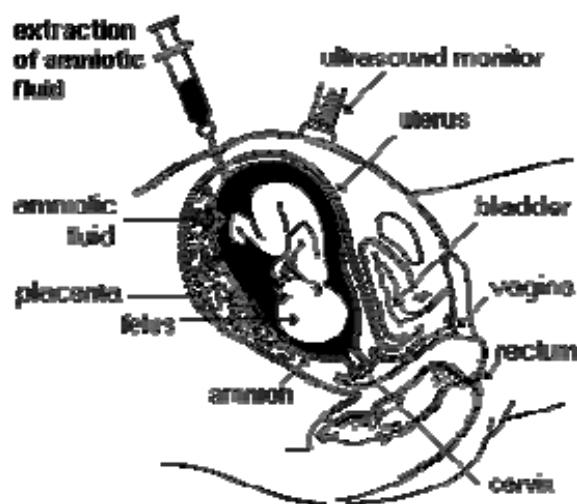
- Shields, P. (1998). Some reflections on respecting children. *J Value Inquiry*, 32, 369-380.
- Shinaman, A., Bain, L. J., & Shoulson, I. (2003). Preempting genetic discrimination and assaults on privacy. *Am J Med Genet*, 120A, 589-593.
- Singer, P. (1975). *Animal liberation*. New York: New York Review Press.
- Singer, P. (1993a). *How are we to live? Ethics in an age of self interest*: The Text Publishing Company.
- Singer, P. (1993b). *Practical ethics* (2nd ed.): Cambridge University Press.
- Skirton, H. (1998). Telling the children. In A. J. Clarke (Ed.), *The genetic testing of children*. Oxford, Washington DC: Bios Scientific Publishing.
- Slavin, L., O'Malley, J., Koocher, G., & Foster, D. (1981). Communication of the cancer diagnosis to pediatric patients: Impact on long-term adjustment. *Am J Psychiat*, 139, 179-183.
- Slotkin, T. (1998). The impact of fetal nicotine exposure on nervous system development and its role in sudden infant death syndrome. In N. Benowitz (Ed.), *Nicotine safety and toxicity*. New York: Oxford Press.
- Snowden, R., & Snowden, E. (1997). *Implications counselling for couples considering Donor Insemination*. London: British Infertility Counselling Association BICA.
- Sorell, T. (2002). The insurance market and discriminatory practices. In J. Burley & J. Harris (Eds.), *A companion to genethics* (pp. 398-407): Blackwell.
- Stephenson, J. (1999). Genetic test information fears unfounded. *JAMA*, 282(23), 2197-2198.
- Strauss, R. (2005). Childhood obesity and self-esteem. *105*(1), e 15.
- Strong, C. (1993). Tomorrow's prenatal genetic testing. Should we test for 'minor' diseases? *Arch Fam Med*, 2(11).
- Taylor, J., Spencer, N., & Baldwin, N. (2000). Social, economic, and political context of parenting. *Arch Dis Child*, 82, 113-120.
- Taylor, M. R. (2001). Genetic testing for inherited breast and ovarian cancer syndromes: important concepts for the primary care physician. *Postgrad Med J*, 77, 11-15.
- Taylor, P. (1981). The ethics of respect for nature. *Environmental Ethics*(3), 197-218.
- Taylor, P. (1986). *Respect for nature*. Princeton: Princeton University Press.
- Taylor, S. D., Otlowski, M. F., Barlow-Stewart, K. K., Treloar, S. A., Stranger, M., & Chenoweth, K. (2004). Investigating genetic discrimination in Australia:

- Opportunities and challenges in the early stages. *New Genet Soc*, 23(2), 225-239.
- Tittle, P. (Ed.). (2004). *Should parents be licensed? Debating the issues*. New York: Prometheus Books.
- Tremblay, M., & Willms, J. (2000). Secular trends in the body mass index of Canadian children. *CMAJ*, 163(11), 1429-1433.
- Triseliotis, J. B. (1973). *In search of origins: The experiences of adopted people*. Boston: Routledge and Kegan Paul.
- Unger, P. (1996). *Living high and letting die: our illusion of innocence*. New York, Oxford: Oxford University Press.
- UNICEF. (2003). *A league table of child maltreatment deaths in rich nations, Innocenti report card No. 5*. Florence: UNICEF Innocenti Research Centre.
- UNICEF. (2005). *Child poverty in rich countries, 2005, Innocenti Report Card No. 6* (No. 6): UNICEF Innocenti Research Centre, Florence.
- van der Steenstraten, I., Tibben, A., Roos, R., Kamp, J. n. d., & Niermeijer, M. (1994). Predictive testing for Huntington Disease: Nonparticipants compared with participants in the Dutch program. *Am J Hum Genet*, 55, 618-625.
- Vineis, P., Schulte, P., & McMichael, A. (2001). Misconceptions about the use of genetic tests in populations. *Lancet*, 357(9257), 709-712.
- Wang, Y., Ge, K., & Popkin, B. (2000). Tracking of body mass index from childhood to adolescence: a 6-y follow-up study in China. *Am J Clin Nutr*, 72, 1018-1024.
- Warren, M. A. (1997). *Moral status: obligations to persons and other living things*. Oxford: Oxford University Press.
- Weatherburn, D., Lind, B., & Ku, S. (1997). *Social and economic stress, child neglect and juvenile delinquency*. Sydney: NSW Bureau of Crime Statistics and Research. Attorney General's Department.
- Wertz, D. (1998). International perspectives. In A. Clarke (Ed.), *The genetic testing of children*. Oxford: Bios Scientific Publishers Ltd.
- Wertz, D. (2000). *Testing children: pros and cons*. Retrieved March 6, 2004, from <http://www.genesage.com/professionals/geneletter/05-01-00/features/children.html>
- Wertz, D., Fanos, J., & Reilly, P. (1994). Genetic testing for children and adolescents. Who decides? *JAMA*, 272(11), 875-881.
- Wertz, D., Fletcher, J., & Berg, K. (2003). *Review of ethical issues in medical genetics*. Switzerland: World Health Organisation.

- Westman, J. (1994). *Licensing Parents: can we prevent child abuse and neglect?* New York: Insight Books.
- Wexler, N. (1992). Clairvoyance and caution: Repercussions from the Human Genome Project. In D. Kevles & L. Hood (Eds.), *The Code of Codes: Scientific and social issues in the Human Genome Project* (pp. 211-243). Cambridge, Mass: Harvard University Press.
- Whitaker, R., Wright, J., Pepe, M., Seidel, K., & Dietz, W. (1997). Predicting obesity in young adulthood from childhood and parental obesity. *New Engl J Med*, 337(13), 869-873.
- Wiggins, S., Whyte, P., Huggins, M., Adam, S., Theilmann, J., Bloch, M., et al. (1992). The psychological consequences of predictive testing for Huntington's disease. Canadian collaborative study of predictive testing. *N Engl J Med*, 327(20), 1401-1405.
- Wolfe, D. A., Crooks, C. V., Lee, V., McIntyre-Smith, A., & Jaffe, P. G. (2003). The effects of children's exposure to domestic violence: a meta-analysis and critique. *Clin Child Family Psychol Rev*, 6(3), 171-187.
- Woodward, A., & Laugesen, M. (2001). *Morbidity attributable to second hand smoke in New Zealand*: Ministry of Health.
- World Health Organisation. (1997). *Proposed international guidelines on ethical issues in medical genetics and genetic services* (No. document WHO/HGN/GL/ETH/98.1): World Health Organisation.
- Wright Clayton, E. (1997). Genetic testing in children. *J Med Philosophy*, 22, 233-251.
- Wynd, D. (2005). *Hard to swallow: foodbank use in New Zealand*. Auckland: Child Poverty Action Group.
- Ybarra, M. L., & Mitchell, K. J. (2005). Exposure to internet pornography among children and adolescents.: a national survey. *CyberPsychology and Behaviour*, 8(5), 473-486.

Glossary

Amniocentesis⁶⁰: A prenatal test in which cells surrounding a foetus are removed in order to examine the chromosome. It is most commonly carried out at 15-18 weeks gestation, although it can be carried out as early as 12 weeks. Ultrasound is used to locate the placenta, and a small quantity of amniotic fluid, which contains cells shed by the developing foetus, is withdrawn through a needle from the amniotic cavity. Cells have to be cultured before chromosomal examination (for example to detect Down's syndrome) or DNA analysis can take place. Genetic diagnosis is not usually possible until 16-20 weeks of pregnancy⁶¹.

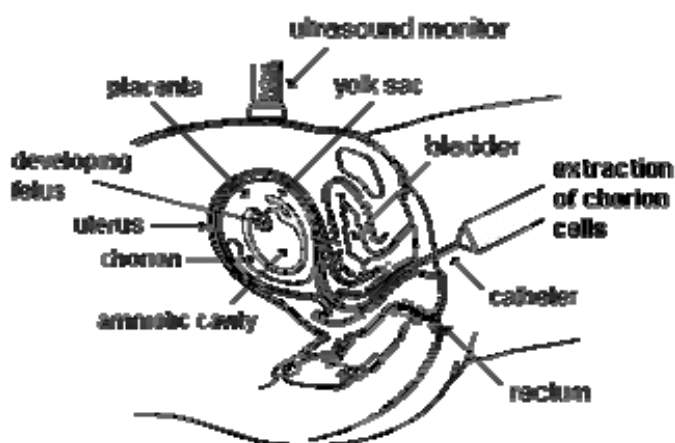


⁶⁰ Diagram taken from: <http://anthro.palomar.edu/abnormal/glossary.htm#chromosome>

⁶¹ http://www.ornl.gov/sci/techresources/Human_Genome/publicat/genechoice/glossary.html

Carrier screening: Performed to determine whether an individual carries one copy of an altered gene for a particular recessive disease. The term recessive refers to diseases that will occur only if both copies of a gene have a disease-associated mutation; thus, each child born to two carriers of a gene mutation has a 25 percent risk of inheriting two altered genes, one from each parent, and thus being affected with the disorder. Examples of carrier tests include those for Tay-Sachs disease, sickle cell anemia, and cystic fibrosis. Couples are likely to have carrier tests if they are at higher risk of having a child with a specific disorder because of their family medical history or racial or ethnic heritage⁶².

Chorionic villus sampling⁶³: A procedure whereby a small sample of chorionic (placental) tissue, which shares the genetic makeup of the foetus is removed for prenatal diagnosis. It is usually performed at about 10 weeks of pregnancy with only minimal discomfort and often allows a genetic diagnosis to be achieved before 12 weeks' gestation. CVS requires first-class ultrasound and an expert and well-trained team⁶⁴.



Chromosome: The thread-like DNA in a cell is divided into several; separate lengths. Each length forms a structure called a chromosome. Most mammalian cells contain two

⁶² <http://www.nhc.govt.nz/publications/PDFs/ScreeningCriteria.pdf>

⁶³ Diagram taken from: <http://anthro.palomar.edu/abnormal/glossary.htm#chromosome>

⁶⁴ <http://www.geneticfutures.com/astronauts/info/sheet3.asp>

copies of every chromosome, with the exception of sex chromosomes in males. Human have 46 chromosomes (23 pairs) in most cells of their body. The sex cells (eggs are sperm) contain only 23 (unpaired) chromosomes⁶⁵.

Chromosomal abnormalities: Abnormalities in chromosome structure follow a chromosome break and, during the repair process, the reunion of the wrong segments of the chromosome. If, following repair, there is a loss or gain of chromosomal material (an unbalanced rearrangement) there can be significant clinical consequences. If there is no loss or gain of chromosomal material (a balanced rearrangement), then the individual is mentally and physically normal. However, there is an increased risk of having chromosomally abnormal offspring because individuals who carry balanced chromosome rearrangements may produce chromosomally unbalanced gametes. Disorders include Trisomy 21 (Down's syndrome), Trisomy 13 and 18, and Turner syndrome⁶⁶.

Congenital disorders: Disorders which are present at birth, not necessarily hereditary. For example the limb deformities cause by the drug thalidomide, or the malformations caused by maternal rubella (German measles) are congenital but not inherited, whereas other forms of malformation may be hereditary⁶⁷.

DNA (deoxyribonucleic acid)⁶⁸: The chemical substance of which a gene is made and which encodes genetic information. A strand of DNA contains genes, areas that regulate genes, and areas that have either no function, or a function we do not (yet) know. DNA is organized as two complementary strands, head-to-toe, with bonds between them that can be "unzipped" like a zipper, separating the strands. DNA is

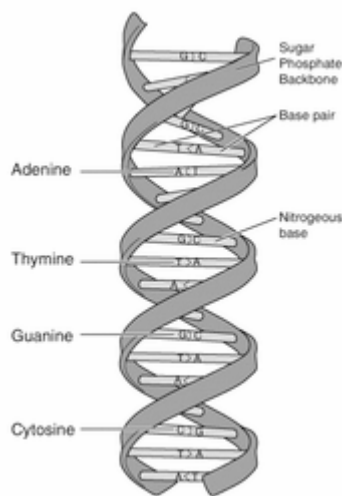
⁶⁵ <http://www.genome.gov/10004766>

⁶⁶ http://www.nuffieldbioethics.org/go/browseablepublications/pharmacogenetics/report_91.html

⁶⁷ http://www.nuffieldbioethics.org/fileLibrary/pdf/genetic_screening.pdf

⁶⁸ Diagram taken from <http://en.wikipedia.org/wiki/DNA>

encoded with four interchangeable "building blocks", called bases, which can be abbreviated; A,T,G,C; each base "pairs up" with only one other base: A+T, T+A, C+G and G+C; that is, an "A" on one strand of double-stranded DNA will "mate" properly only with a "T" on the other, complementary strand. The order does matter: A+T is not the same as T+A, just as C+G is not the same as G+C. The following is a schematic representation of the DNA which illustrates its double helix structure⁶⁹.



Dominant: The form of inheritance in which a genetic disorder or character shows itself when only one of the two copies of the gene is abnormal⁷⁰.

Familial hypercholesterolaemia: Familial hypercholesterolaemia is the name given to a specific inherited disorder in which the gene causes high levels of blood cholesterol from birth. It is dominantly inherited and individuals with a single abnormal gene have a greatly increased risk of developing heart disease by the age of 50 years; those who inherit the abnormal genes from both parents have extremely high blood cholesterol and many develop heart disease in their teens. It is estimated that about 1 in 500 individuals

⁶⁹ http://www.nuffieldbioethics.org/go/browseablepublications/pharmacogenetics/report_91.html

⁷⁰ http://www.nuffieldbioethics.org/fileLibrary/pdf/genetic_screening.pdf

are born with the disorder but the very serious (both genes affected) condition only occurs in about 1 in 1,000,000. Mode of inheritance is dominant⁷¹.

Familial adenomatous polyposis (FAP): A hereditary disease of multiple adenomatous polyps of the large intestine, and occasionally other parts of the gastrointestinal tract. FAP is an inherited condition caused by a mutation in a gene that is inherited in an autosomal dominant way. This means that half the children of an affected parent will have FAP, but the remaining unaffected children do not have the gene to pass on to their offspring. The condition is characterised by the formation of polyps, also known as adenomas (because they are at a pre-cancerous stage, where they may or may not develop into cancerous cells). By the time an affected individual is 15-20 years old, hundreds of adenomatous polyps will have developed in the colon. Although each individual polyp has a fairly low risk of becoming cancerous, the patient usually has so many polyps that colon cancer is almost inevitable by the age of 50. Commonly this cancer occurs much earlier in adult life unless prophylactic (preventive) colectomy (the removal of the colon) is done⁷².

Gene: The fundamental physical and functional unit of heredity consisting of a sequence of DNA, occupying a specific position within the genome⁷³.

Gene expression: The process by which information contained in a gene is transcribed to produce functional RNA molecules which are then translated to produce proteins⁷⁴.

Genetic counselling: Education and guidance offered by professional advisors in order to help people make informed decisions based on genetic knowledge. Genetic

⁷¹ http://www.nuffieldbioethics.org/fileLibrary/pdf/genetic_screening.pdf

⁷² <http://www.colonrectal.org/patientinfo/definitions/definitions.htm>

⁷³ <http://ghr.nlm.nih.gov/ghr/glossary/gene>

⁷⁴ http://www.nuffieldbioethics.org/go/browseablepublications/pharmacogenetics/report_91.html

counselling is intended to help a person understand the meaning of specific information about his or her genes. It also is intended to help a person decide whether to have a genetic test performed or what to do with information provided by such a test⁷⁵.

Genetic disease or disorder: Conditions which are the result of alterations in the genetic make-up of an individual. They may be the direct consequences of defects in single genes (mutations); or in whole chromosomes, parts of which may be lost, duplicated or misplaced; or from the interaction of multiple genes and external factors⁷⁶.

Genetic test: A test to detect the presence or absence of, or change in, a particular gene or chromosomes. This can be done directly, by analyzing the DNA of an individual, or indirectly, by examining the products of their DNA, such as RNA or proteins. In some cases, the presence or absence of particular genes can be determined by consideration of the family history of an individual, or simply by clinical observation⁷⁷.

Genome: The total genetic complement of an individual or of a species⁷⁸.

Genotype: An individual's genotype is their entire genetic constitution, as distinguished from their physical characteristics. See also phenotype⁷⁹.

Human Genome Project: The scientific mission to "read" the order of bases as they appear in the DNA of human chromosomes. The Human Genome Project actually is not one project, but rather many hundreds of separate research projects being conducted

⁷⁵ http://www.ornl.gov/sci/techresources/Human_Genome/publicat/genechoice/glossary.html

⁷⁶ http://www.nuffieldbioethics.org/fileLibrary/pdf/genetic_screening.pdf

⁷⁷ http://www.nuffieldbioethics.org/go/browseablepublications/pharmacogenetics/report_91.html

⁷⁸ Ibid

⁷⁹ Ibid

throughout the world. The objective is to create a directory of the genes that can be used to answer questions about what specific genes do and how they work⁸⁰.

Huntington's disease (HD): It is a progressive brain disorder that causes uncontrolled movements, mental and emotional problems, and loss of thinking ability (cognition). HD is a familial disease, passed from parent to child through a mutation in the normal gene. Each child of an HD parent has a 50-50 chance of inheriting the HD gene. If a child does not inherit the HD gene, he or she will not develop the disease and cannot pass it to subsequent generations. A person who inherits the HD gene will sooner or later develop the disease. Whether one child inherits the gene has no bearing on whether others will or will not inherit the gene. Some early symptoms of HD are mood swings, depression, irritability or trouble driving, learning new things, remembering a fact, or making a decision. As the disease progresses, concentration on intellectual tasks becomes increasingly difficult and the patient may have difficulty feeding himself or herself and swallowing. The rate of disease progression and the age of onset vary from person to person. A genetic test, coupled with a complete medical history and neurological and laboratory tests, help physicians diagnose HD. Presymptomatic testing is available for individuals who are at risk for carrying the HD gene. In 1 to 3 percent of individuals with HD, no family history of HD can be found. Mode of inheritance is dominant. The abnormal gene was isolated in March 1993. The symptoms most commonly first appear in individuals of between 40 and 50 years of age, with death occurring 15-20 years later⁸¹.

Molecular genetics: The study of the molecular structure and function of genes⁸².

⁸⁰ http://www.ornl.gov/sci/techresources/Human_Genome/publicat/genechoice/glossary.html

⁸¹ <http://ghr.nlm.nih.gov/condition=huntingtondisease/show/print;jsessionid=F230041DF...>

⁸² <http://www.ncbiotech.org/biotech101/glossary.cfm>

Multifactorial: A term which denotes that many factors, often environmental (such as diet and smoking) contribute to the development of a disease. Often used interchangeably with polygenic⁸³.

Mutation: The modification of a DNA sequence that can potentially result in a change in the function of a gene. Mutations may be caused by mistakes during cell division, or they may be caused by exposure to DNA-damaging agents in the environment. Mutations can be harmful, beneficial, or have no effect. If they occur in cells that make eggs or sperm, they can be inherited; if mutations occur in other types of cells, they are not inherited. Mutations in genes are the cause of genetic disease⁸⁴.

Newborn screening: Newborn screening allows for the earliest possible post-birth detection enabling early intervention or therapy. Within the first 2 or 3 days of life, the baby's heel is pricked and a small sample of blood is applied to a card (called a Guthrie card after the scientist who developed a blood test that could determine whether newborn babies had PKU). In general, consent to screening is not required; however, parents can refuse screening if they notify the health care provider in advance. New technologies and gene discoveries are leading to rapid expansions in newborn screening. Use of a new screening technique, known as tandem mass spectrometry, allows screening for more than 20 inherited metabolic disorders with a single test⁸⁵.

Pharmacogenetics: The study and applications of the genetic basis of individual variations in drug sensitivity, drug resistance, and drug metabolism⁸⁶.

⁸³ http://www.privacy.gov.au/publications/HRC_PRIVACY_PUBLICATION.word_file.p6_4_72.44.doc

⁸⁴ <http://www.stjude.org/glossary?searchTerm=M>

⁸⁵

[http://dnapolicy.stage.labvelocity.com/genetics/newborn.jhtml;\\$sessionid\\$DDGALPQAAASGEQBICNWR3KQ](http://dnapolicy.stage.labvelocity.com/genetics/newborn.jhtml;$sessionid$DDGALPQAAASGEQBICNWR3KQ)

⁸⁶ See: McConkey, E.H. (2004). *How the human genome works*. Boston: Jones and Bartlett Publishers.

Phenotype: The observable or measurable traits of an individual as produced by its genotype and the environment. See also genotype⁸⁷.

Phenylketonuria (PKU): The mode of inheritance is recessive. PKU is a rare inherited disorder. Affected individuals inherit the abnormal gene from each parent and are unaffected at birth, but with the introduction of feeding, a substance in the blood (phenylalanine) builds up and causes brain damage, so that untreated children become severely mentally handicapped. Every baby in NZ has a blood test for phenylalanine at about 6 days of age and if the diagnosis is confirmed, a special diet is started. With rigorous dietary control mental development can be normal. Dietary control has to be continued at least into late childhood and possibly throughout life⁸⁸.

Polycystic kidney disease (PKD): Mode of inheritance in infantile form is autosomal recessive (ARPKD). In adult form, mode of inheritance is dominant (ADPKD). Infantile polycystic kidney disease is present at birth. It is inherited in a recessive manner and can be detected before birth by ultrasound. Adult polycystic kidney disease is a common dominantly inherited disorder, with a worldwide prevalence of between 1 in 500 and 1 in 1,000 individuals. Symptoms do not usually appear until around 40 years of age. Small cysts may be detected before birth by ultrasound examination; they enlarge slowly throughout life. About 50% of affected individuals will develop severe kidney failure by age 70⁸⁹.

Polygenic: Describes traits or diseases caused by the interaction of multiple genes, each of which has a relatively small effect⁹⁰.

⁸⁷ http://www.nuffieldbioethics.org/go/browseablepublications/pharmacogenetics/report_91.html

⁸⁸ <http://www.pku.com/Footer/Glossary.aspx#p>

⁸⁹ http://www.privacy.gov.au/publications/HRC_PRIVACY_PUBLICATION.word_file.p6_4_72.44.doc

⁹⁰ <http://www.uvm.edu/~cgep/Education/Glossary.html>

Pre-implantation genetic diagnosis (PGD): In conjunction with IVF, where a recognised practitioner removes one or two cells from an embryo, for those cells to be tested for specific genetic disorders/characteristics before embryo transfer takes place. PGD enables physicians to identify genetic abnormalities in embryos and to select for implantation only those embryos that are found not to have the abnormality. PGD was developed so that couples at risk of having children with serious genetic disorders could increase their chances of having a child without the disorder⁹¹.

Prenatal diagnosis: The term *prenatal diagnosis* refers broadly to a number of different techniques and procedures that can be performed during a pregnancy to provide information about the health of a developing foetus. *Screening tests* indicate whether the foetus has an average, greater than average, or below average risk of being affected by a particular genetic condition or birth defect. When the result of a screening shows increased risk, the pregnant patient may be offered other *diagnostic tests* to confirm whether the foetus is, in fact, affected. Diagnostic tests may also be offered directly to women whose pregnancies are considered high risk because of age, family history or other factors. It is important to note that none of these tests guarantee the birth of a healthy baby. The tests are designed to identify the presence of specific conditions or abnormalities, and the absence of such specific conditions does not necessarily suggest the overall health of the baby⁹².

Presymptomatic genetic testing: A test performed on a person who has no symptoms of a specific disorder at the time of testing to determine whether or not he/she has a

⁹¹ <http://www.hfea.gov.uk/Glossary?show=P>

⁹² http://en.wikipedia.org/wiki/Prenatal_testing

gene which is almost certain to cause symptoms of the disorder to appear at some time in the future. Often used interchangeably with predictive genetic testing⁹³.

Recessive: There are two copies of each gene. If a healthy individual has one working copy of a gene and one non-working copy, the mutation is described as being hidden or 'recessive' by the working copy of the gene. An individual with this genetic makeup is a 'carrier' of a recessive gene mutation. An individual with two non-working copies would be affected with the genetic condition (dominant)⁹⁴.

Screening: A test done on people at risk of developing a certain disease, even if they have no symptoms. Screening tests can predict the likelihood of someone having or developing a particular disease. The principal screening measure for breast cancer is mammography. In 2003 the NZ National Health Committee defined screening as “*a health service in which members of a defined population, who do not necessarily perceive they are at risk of, or are already affected by, a disease or its complications, are asked a question or offered a test to identify those individuals who are more likely to be helped than harmed by further tests or treatments to reduce the risk of disease or its complications*”⁹⁵.

Sequencing: Determination of the order of the nucleotides (or base pairs) in a DNA or RNA molecule, or the order of amino acids in a protein⁹⁶

RNA (ribonucleic acid): A chemical similar to DNA from which proteins are made. Unlike DNA, RNA can leave the nucleus of the cell⁹⁷.

⁹³ See: National Health and Medical Research Council. (2000). *Ethical aspects of human genetic testing: an information paper*. Canberra: NHMRC.

⁹⁴ <http://www.medgen.ubc.ca/wrobinson/mosaic/glossary.htm>

⁹⁵ <http://www.nhc.govt.nz/publications/ScreeningCriteria.pdf>

⁹⁶ <http://www.kidsnutrition.org/consumer/archives/genglossary.htm>

⁹⁷ Ibid

X-linked: Trait or disease tied to genes on the X chromosome, which is one of the sex chromosomes that determine gender of an organism. Males have one X and one Y chromosome, while females have two X's. Thus if a defective gene that is X-linked is passed on by one parent to a female child, she will become a carrier, but in many cases will not develop symptoms, because the other gene is normal. When a defective X-linked gene is inherited by a boy, he typically will develop symptoms, because there is only one gene to do the job⁹⁸.

⁹⁸ <http://www.myelin.org/glossary.htm#X>