DNA AND FAMILY MATTERS

Thesis for Degree of Doctor of Philosophy (Ph.D)
Submitted to Charles Sturt University Oct 2011

Madeline Kilty
BA (hons)
# CONTENTS

- Certificate of Authorship ................................................................. 4
- Professional Editorial Assistance .................................................... 5
- Acknowledgements ........................................................................ 6

## Abstract
- 7

## DNA And Family Matters
- Introduction .................................................................................. 8

## Definitions And Explanations
- Conceptual Frames ......................................................................... 11
- Methodology ................................................................................... 12

## 1 Children’s Rights
- The Right To Know .......................................................................... 14
- What Are Rights? ........................................................................... 16
- Rights Theories .............................................................................. 18
- The Will Theory ............................................................................. 19

### Solutions To Counteract The Problem Of Children’s Lack Of Rights On The Will Theory Account
- Benefits Of Talking In Terms Of Rights ......................................... 22
- Criticism Of The Will Theory ......................................................... 26
- The Interest Theory ....................................................................... 27
- Criticism Of The Interest Theory .................................................. 28
- A Response To This Criticism ....................................................... 29
- Conclusion ..................................................................................... 30

## 2 The CRC Rights
- Other Human Rights Treaties ......................................................... 31
- Advantages Of The CRC For Children Over Preceding Rights Treaties ......................................................... 33
- Criticism Of The CRC ................................................................. 35

### Criticism Regarding The Ambiguity Of The Terms Used In The CRC
- The Implementation Handbook ...................................................... 36
- The Handbook’s Explanation Of Terms Used In Article 7 Of The CRC ......................................................... 39
- Who Is The Right-Holder And Addressee Of Article 7(1) Of The CRC ......................................................... 41
- Australian Government As Addressee Of The Right In Article 7 ........................................................................ 42
- Parents As Addressees Of The Right In Article 7 .......................... 43
- Discussion On The Apportioning Of Obligations ....................... 45
- In Defence Of Addressing Rights In The Form Of A Convention Like The CRC ......................................................... 46
- In Defence Of Addressing Rights In The Form Of A Convention Like The CRC ......................................................... 48
- Conclusion ..................................................................................... 50

## 3 Why Information About Genetic Parents Is Beneficial For Children To Have
- Explanation ................................................................................... 52
- Health Benefits Of Knowing Genetic Parents’ Identities .......... 53
- Benefits Of Information In Cases Of Organ And Tissue Transplant ......................................................... 54
- Arguments Against The Importance Of Information About Genetic Parent For Health Reasons .......... 55
- The Importance Of Providing Information About Genetic Parents For Health Reasons ......................................................... 57
- The Potential Risk Of Incest Occurring ....................................... 65
- Problems With This View .............................................................. 68
- Response To The Arguments Regarding Incest ......................... 69
- The Arguments Regarding The Availability Of Information About Siblings ......................................................... 70
- Increased Autonomy From Having Information About Genetic Parents ......................................................... 71
- Impact On Genetic Parents ............................................................ 74
- Other Objections That Are Raised In The Following Chapters ........................................................................ 75
- In Defence Of Providing Information ........................................ 75
- Conclusion ..................................................................................... 77

## 4 Children Want To Know
- Adoptees And Donor-Offspring Have A Strong Desire To Gain This Information ......................................................... 79
- Abandonment Issues ..................................................................... 82
- Narrative Identity .......................................................................... 82
- The Psychological Search For Self ................................................. 83
- The Possibility Of Suffering Genealogical Bewilderment If Denied Information Until Later In Life ......................... 84
- Adrienne Kraft’s View .................................................................. 86
- Problems With Kraft’s View .......................................................... 89
| Counteracting The Problems Of Genealogical Bewilderment And Shock | 91 |
| Conclusion | 92 |
| **5 Adopted Children** | 94 |
| Adoption Statistics In Australia | 94 |
| The Benefits Of Closed Adoption | 97 |
| Some Problems With Closed Adoption | 99 |
| Other Problems With Secret Adoption | 101 |
| Parents Support Open Adoption | 105 |
| Legislation On Open Adoption | 105 |
| The National Move Away From Secret Adoptions | 106 |
| What Open Adoption Involves | 108 |
| Types Of Adoptions In Australia | 110 |
| Difficulties In Obtaining Information For Local Adoptees | 110 |
| Difficulties In Obtaining Information For Overseas Adoptees | 111 |
| Problems With Open Adoption For Genetic Parents | 112 |
| Response To The Views Of These Genetic Parents | 114 |
| Problems With Open Adoption For Adoptive Parents | 117 |
| Response To These Views | 118 |
| Conclusion | 120 |
| **6 Donor-Conceived Children** | 122 |
| Australia Moves Away From Anonymous Gamete Donations | 122 |
| The Global Move To Remove Donor Anonymity | 124 |
| Arguments Used In Support Of Anonymous Gamete Donation | 125 |
| Arguments Used In Support Of Anonymous Gamete Donation Are No Longer Justified | 125 |
| The CRC And The Global Move Away From Anonymous Births | 128 |
| David Velleman’s Views | 129 |
| Created To Be Denied Information about Genetic Identity | 130 |
| In Response To Velleman | 130 |
| Arguments In Support Of Velleman | 131 |
| Slight Advantages To Commissioning Parents | 132 |
| Self-Knowledge And Identity Formation | 133 |
| Arguments Against The Importance Of Self Knowledge And Identity Formation | 134 |
| The Importance Of Genetic Ties | 135 |
| Problems With This View | 136 |
| In Defence Of Velleman’s View | 137 |
| Conclusion | 137 |
| **7 Family Matters** | 139 |
| Explanations | 139 |
| Distinction Between Donor-Offspring, Adoptees, And Children Of Misattributed Paternity | 140 |
| Open Marriage | 140 |
| Parentage Identity Unknown | 141 |
| The CRC And The Issue Of Misattributed Paternity | 141 |
| The Case For The Family Unit | 143 |
| Consequence Of Divorce For The Child | 144 |
| Arguments In Support Of Disclosure In Cases Of Deliberate Misattribution Of Paternity | 145 |
| One Solution To This Dilemma | 146 |
| Problems With This Solution | 146 |
| Discussion | 147 |
| Problem Cases Of Rape | 148 |
| Problem Cases Of Incest | 149 |
| Problem Cases Of Abusive Relationships | 149 |
| Conclusion | 150 |
| **8 The Benefits Of Mandatory DNA Testing Of Newborns** | 152 |
| China’s DNA Database | 152 |
| Argentina’s DNA Parentage Testing | 154 |
| One Problem With Argentina’s Mandatory DNA Testing Of Children | 155 |
| Germany’s DNA Testing | 156 |
| Problem With The German View On DNA Parentage Testing | 157 |
| Secret Paternity Testing Is Problematic | 158 |
| Suspcion About Paternity | 159 |
Certificate of Authorship

“I Madeline Kilty hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person nor material which to a substantial extent has been accepted for the award of any other degree or diploma at Charles Sturt University or any other educational institution, except where due acknowledgment is made in the thesis. Any contribution made to the research by colleagues with whom I have worked at Charles Sturt University or elsewhere during my candidature is fully acknowledged.

I agree that this thesis be accessible for the purpose of study and research in accordance with the normal conditions established by the Executive Director, Library Services or nominee, for the care, loan and reproduction of theses.”

................................................................. 20/11/2011
Signature                                      Date

*Subject to confidentiality provisions as approved by the University.
Professional Editorial Assistance

This work was professionally edited by Matt Peterson who works in the field of philosophy. Matt was paid as a professional editor to check the grammar and style in this work. The discussion presented in this work is entirely that of the author.
Acknowledgements

Thanks to my supervisors Profs. Marilyn Freedman and Tom Campbell for their comments.
Abstract

This thesis challenges the idea of genetic parentage anonymity and defends a governmental policy of mandatory DNA testing of all newborns and their presumed genetic parents in order to determine actual genetic parentage. The United Nations Convention on the Rights of the Child accords children a number of rights. Article 7 of this convention provides children with a right to know their genetic parents. I argue that the concept of rights is the best way of addressing children’s welfare. As a consequence, the Interest Theory of rights is considered here as the better of two theories (Interest Theory and Will Theory) that could be used to account for children having the rights in this convention. Article 7 affects all children, but it is particularly relevant to children who have been adopted, children of gamete donation and children of misattributed paternity. This right is important for a number of reasons, including children’s wellbeing. Genetically related illnesses may pass from generation to generation, so a person with knowledge of genetic family health problems could be in a better position to take measures to address their health problems than a person without this information. Another reason for thinking it important that children have this right is that siblings should be made aware of each other in order to avoid forming incestuous relationships. This information is more important now than ever before because of the growing percentage of children being born as a result of gamete donation and the number of siblings and half-siblings being born as a result of donations by a single donor in the same locality. I discuss problems of identity and the possibility of children suffering psychological harms as a result of only being given this information in later life. As one's autonomy may be impacted by lack of genetic family information, this also forms part of my discussion. This thesis takes up discussion on the reasons for and against children having access to this information. One way that children could have access to this information is through mandatory DNA testing of newborns and their alleged genetic parents and storing the results in a database. By adopting this proposed paradigm shift we could identify genetic parentage and then make the information available to children at an appropriate age. The final topic addresses privacy issues related to collecting and storing information gathered from DNA in a database.
DNA And Family Matters

Introduction

Accurate information about genetic parentage was not so readily available in the past. However, advances in human genomics, in particular deoxyribonucleic acid (DNA) testing, now allow people to determine, with a great deal of accuracy, their genetic kinship. Currently, for instance, DNA testing is rated 99.99% accurate in determining paternity and is 100% accurate in determining non-paternity.\(^1\) Because DNA testing can provide such accurate information about genetic relationships, it is now routinely used in Australian legal cases to determine paternity and non-paternity for child support evaluation, for instance.\(^2\) As a result, DNA parentage testing has become a vital means (and in some cases the only means) of obtaining certain information necessary for solving the question of who is genetically related to whom.

The American Association of Blood Banks’ (AABB) records show that as many as 30% of children tested by men suspected of fatherhood are not the genetic children of those men.\(^3\) If the figures from the AABB are accurate, then there may be an increase in the number of cases of children being secretly DNA tested by alleged fathers suspicious about their genetic links to their children. If this figure is also indicative of Australian children, then this may apply to their fathers also followed by an increase in the number of appeals before the courts for exemption of child support payments from those proved to be non-genetic fathers.

Child support reasons aside, it is sometimes beneficial to know who we are genetically related to. Knowing who our genetic parents are, for instance, could help us to determine our predisposition to genetic health problems and could prevent us unknowingly marrying our siblings or half-siblings. Knowing something about our predisposition to health problems would allow us to take measures to prevent, reduce or control the onset or effects of inherited diseases. Many take the view that incest is problematic and that it has the potential to cause harms. Unknowingly marrying one’s sibling has become a greater risk than ever before as more and more people choose donor gametes to create a family, resulting in a number of siblings and half-sibling donor-conceived children living in the same jurisdiction, but within different households. In some cases these children are unaware that they were donor-conceived and have siblings and half-siblings, let alone the fact that they are living close by.

\(^1\) easyDNA Australia, 2006, no pagination (np).
\(^3\) American Association of Blood Banks, 2006, p. 4.
In addition, information about who we are genetically related to would allow us more autonomy in making health and reproductive decisions. In chapter 3, I address the risks associated with health, incest and autonomy when this information is withheld over a child’s lifetime. Some children may be denied knowledge of their genetic parents until they are adults, and others may never be told. Evidence suggests that children denied such important information about themselves until they are older are at risk of developing psychological problems, such as genealogical bewilderment\(^4\) (I take up this issue in chapter 4). Some donor-offspring, adoptees and children of misattributed paternity, for instance, are routinely denied certain important truths about their genetic parentage and, therefore, about themselves. I take up the discussion on adoptees, donor-offspring and children of misattributed paternity in chapters 5, 6 and 7 respectively.

Withholding information about genetic parents or providing false or misleading information about them can, through habitual practice, lead a child to accept an artificial account of their identity that could be passed on through future generations, depriving those generations too from providing a factual account of their genetic family history.

It is now accepted among some philosophers that children ought to have a moral right to this information about themselves. My question is whether children ought to have a legal right to information about the identities, that is, the names of their genetic parents. This is in response to the United Nations Convention on the Rights of the Child (hence forth the CRC), which provides children with a legal right, as opposed to a moral right, to know their genetic parents (I return to the CRC in chapter 2). Although legal rights are most often based on moral rights, the two are not the same. For instance, I may have a moral right to be treated with respect by my children, but I do not have a legal right to their respect. The Australian government ratified the CRC in 1990,\(^5\) providing grounds for legislation to enforce Article 7 from that time. Having signed on to and ratified this convention, some might consider that the Australian government now has a duty to uphold the rights the convention contains. However, some others may believe that children ought not to have any rights at all because they do not qualify as right-holders. As a result, I begin with this discussion in chapter 1.

However, if we consider that children ought to have legal rights and that the rights contained in the CRC are the rights best suited to children, then one way to ensure that children do have at least one of these rights (the right in Article 7 to have information about


\(^5\) Department of Foreign Affairs and Trade, 1995, np.
their genetic parents) is to carry out DNA testing on newborns and their alleged parents to identify their actual genetic parents. One problem with providing this information to a child, however, is that it could adversely impact them and their family. For instance, if it is exposed that the child is the result of infidelity, this could adversely affect the child and it could lead to a family break-up or worse. As a result, I acknowledge that there are some cases where it may be better to withhold information about the identities of genetic parents from some children; for instance, if it puts their lives or personal wellbeing at risk. I take up discussion on these sorts of cases in chapter 7.

However, given that there may be good reasons for children to have information about their genetic parents, it is important to note that there are very few reliable means other than DNA testing to ensure that children obtain this information. That being the case, then I will argue that we should consider DNA testing newborn children and their alleged genetic parents to establish a child’s genetic parentage. It is thought that this would be best carried out at the birth of the child. Since DNA technology is now highly accurate, readily available and accepted as conclusive proof of parentage by the government and legal system, I propose that there is no good reason why we ought not to avail ourselves of this useful tool. Naturally, should mandatory parentage testing become a reality, we may have to consider imposing a penalty for parents who refuse to submit to testing (I discuss these issues in chapter 8).

Obviously, privacy and data protection are major concerns should a government seek to establish and maintain a database of DNA information of its citizens. As such, I will consider privacy issues and data integrity and protection where information is obtain from DNA and contained in a government or government regulated database in chapter 9.

The main focus of this work, however, is on the benefits and harms involved in denying children information about the identities of their genetic parentage. To this end, I focus on cases of adoption, donor conception, and the less-considered problem of misattributed paternity. Given that there are risks involved in withholding this information from children throughout their lives and also with withholding it for prolonged periods of a child’s life, it is considered that people who know the identities of their genetic heritage are, in some ways, better off than those who do not. Of course, if that is the case, then those who have information about the identities of their genetic family have an important good that those without this information lack and, therefore, these latter people are disadvantaged in some way.
Definitions And Explanations

The terms of the CRC are based, most generally, on the concept of children defined as “persons up to the age of 18 years.”6 The convention adds the proviso, “unless, under the law applicable to the child, majority is attained earlier.”7 I apply the definition of ‘children’ as persons up to the age of 18 years, since this is most generally what we mean when we speak of children in Australia.

When I use the terms ‘obligations’ and ‘duties’, I make no distinction between the two. That is, I treat them as equivalent in meaning.

While there are various ways of defining the terms ‘paternity fraud’, ‘misattributed paternity’ and ‘misidentified paternity’, I deal with them all in terms of a man being led to believe he is the genetic father of a child when he is not. I may use these terms interchangeably. However, I fully acknowledge that in some cases there is no attempt on the mother’s part to be deliberately deceitful about her child’s genetic father.8 She simply may not know his identity or is mistaken about it and unintentionally misidentifies the wrong man.

In the case of adopted children, reference is made by various authorities to ‘birth parents’ and ‘birth mothers’. In light of the fact that these terms can be misleading due to the fact that a surrogate mother may be the birth mother without being the genetic mother, I refrain from using these terms. Where these terms are used in citations, I believe that it is genetic parents that are intended by these authorities.

When referring to parents, I use the terms ‘genetic parents’ to denote the genetic parents of a child. I use the term ‘social parents’ to identify those parents who have custody of a child, but are not the genetic parents of the child. Thus social parents denote adoptive parents and gamete donor recipient parents. Foster parents would also come under the heading of social parents. I use the term parent when I am referring to both types of parent. This is for no other reason than to provide clarity.

My main focus is on a child’s right to information about the identities of her genetic parents, as supported by Article 7(1) of the CRC, and instances where this right may conflict with her other rights. I do not discuss the morality of abortion, medical ethics, in-vitro-fertilisation (IVF) treatments, donor contributions of gametes or surrogacy. Again, these topics require greater attention in their own right than can adequately be allotted here.

---

6 Ibid.
7 Ibid.
8 For further discussion on the morality of deceitful non-disclosure in cases of misattributed paternity see Madeline Kilty 2010.
While my thesis merely responds to one question in relation to children’s rights, that is, the right as expressed in Article 7 of the CRC, it raises a number of issues not least of which is whether or not other rights in the CRC can be justified.

Conceptual Frames

My thesis encompasses such areas of philosophy as children’s rights and interests; parental and governmental duties and obligations; and data protection of personal information and the costs to the state of instituting mandatory DNA testing of newborns and their genetic parents. This work also focuses on the family unit and the impact of truth telling in cases of misattributed paternity. I include discussion on the advantages and disadvantages of children having access to information about the identities of their genetic parents via DNA-based parentage testing. Included also are some recent statistics from relevant studies and news reports, which I use to show that the problems discussed in this thesis are real and extensive and not theoretical and that they are worth ethical consideration. Reference to current and past laws governing adoption and donor conception is widely discussed because these laws have a bearing on the current norms surrounding the provisions regarding information about genetic parents. This information grounds my thesis in contemporary thought regarding secret adoptions and anonymous gamete donations.

Methodology

My methodology is to apply the process of analytical philosophy by way of reason and argument to the problem of whether children ought or ought not to have a legal right to information about their genetic parents. I compare current norms within philosophical theory to reach an ethical conclusion on current societal trends, and I provide a personal response to the problem of providing access to information about the identities of genetic parentage should it be established that children ought to have a legal right to this information. I utilize the current available empirical data on this topic to show the extent of the problem and its effects. For instance, an analysis of the empirical data shows that some children who only find out in later life that someone they thought was their genetic parent is not can suffer psychologically harms. Sometimes a child may discover the truth about his genetic parentage when divorce of his parents is followed by DNA testing for parentage (see Magill vs. Magill case in chapter 8) or when tissues and organs are matched for transplant operations (see Erica Lucast’s paper Informed Consent and the Misattributed Paternity Problem in Genetic Counseling (2007) for discussion on the ethical ramifications of this problem, which I do not
discuss here). There is also some evidence to suggest that truth telling can have an adverse affect on otherwise secure children and their family relationships (see chapter 7). Empirical evidence suggests that we can help solve these problems for children, for example, by accurately identifying genetic parentage early in a child’s life. I propose that actual genetic parentage be established early in a child’s life through mandatory DNA testing of newborns and their alleged genetic parents. I propose this solution in order to help solve some of the ethical problems associated with non-disclosure of genetic parentage.
I

Children’s Rights

The CRC is a human rights treaty. Human rights address specifically the safeguard of human wellbeing and fundamental interests. Human rights are generally considered to be universal, that is, recognised by all people as an important means of protecting their wellbeing and fundamental interests. In those countries where human rights are recognised and upheld, people generally have a right not to be tortured, for instance. In countries where human rights are recognised and upheld, some human rights can be the basis for laws based on their moral foundation. So for instance, while a citizen in those countries may have a right not to be tortured, there may also be a law against torturing the citizen. Where there are laws against torturing people, perpetrators can be legally held accountable and penalised. Thus, in countries where human rights are recognised, upheld and made law, they are a very important means of citizen protection. Other types of rights include animal rights and property rights, to name only a couple of the many rights that are said to currently exist. Animal rights and property rights were designed to protect animals and property. As a human rights document, the CRC was designed to protect children’s wellbeing and fundamental interests (I discuss the CRC in more detail in the following chapter). It is generally considered that human rights, whether enforced in law or not, are universal and of paramount importance and sometimes of overriding moral significance in recognising the value of human life and dignity. In this chapter, I provide a brief account of the rights position I start from and why.

The Right To Know

While the CRC accords children a great many rights, my focus is specifically on positive morality (“the morality actually accepted and shared by a given social group”)⁹, which pertains to the article of rights in the CRC that I am addressing. The social group addressed in this particular case is Australian citizens. Thus I am looking at this problem from the perspective of the morality shared and accepted by Australian citizens. That being the case, the issue at hand is whether Australian children ought to have as a legal right the right contained in Article 7(1) of the CRC, according to which:

The child shall be registered immediately after birth and shall have the right from birth to a name, the right to acquire a nationality and, as far as possible, the right to know and be cared for by his or her parents.¹⁰

---

¹⁰ Department Of Foreign Affairs And Trade, 1995, (np).
I interpret Article 7(1) as entitling children to information about their genetic parents in particular (I return to the interpretation of ‘parent’ in the CRC in the following chapter). On my view, this right holds to the extent that information about the identities of those genetic parents is available to those who would be in a position to discharge the right. On my interpretation of Article 7(1), those who are in the relevant position to discharge the right should, if they have the information, make it available to the child at an appropriate age (I come back to this issue in chapter 4).

Thus, I defend the claim in this thesis that children ought to have a legal right to information about the identities of their genetic parents. I do not defend the additional claim that children ought to have the legal right to be cared for by those parents. Nor do I defend the idea that they ought to have the legal right to be acquainted with their genetic parents in the sense of meeting them. However, I do support the view that they should have the counter right to waive their right to this information if they so choose. In other words, this information ought not to be forced on children if they choose not to have it. I fully recognise that some children will not want to know anything about their genetic parents. However, I hold that information about those parents should be made available for children to access should they ever change their minds and want to know. This is because it is recognised that people often change their minds as time passes. As a result, being uninterested in this information at one point in time may not hold true for all time. I discuss one way that children could obtain this information in a later chapter.

If it can be established that children ought to have a legal right to information about the identities of their genetic parents, then this may go part of the way to establishing that children ought to have a legal right to know those parents by acquaintance. However, I do not make that further argument here. My claim is simply that children should have the legal right to information about the identities of their genetic parents. It is thought that this information would amount to their genetic parents’ names. There are a number of reasons for thinking that this information is beneficial for children to have, which I discuss in chapter 3. However, it is also thought that information about genetic parents’ nationalities, their susceptibility to genetic health problems and the number and identities of their children is information that would be beneficial for children to have. However, this additional information should be sought out by children themselves (or social parents on their children’s behalf), should they wish to have it. It is thought that genetic parents should supply this additional information in case it is ever sought. It is thought that they should provide this information for reasons of
beneficence and in order to reduce risk of harms to their offspring. This is information that children would naturally have access to if they were reared by their genetic parents.

I use the concept of rights to express the moral and legal obligations of (certain) adults to make information about the identities of genetic parent’s available to each child where possible. However, it should be noted that some rights theorists reject the concept of rights for expressing moral requirements to children. To defend my use of this concept, I take a preliminary look at the concept of rights and the two most popular rights theories in current philosophical debate in order to compare them on this issue. But before I focus on these rights theories, I look at the class of right my thesis is concerned with in order to identify the type of right I am discussing, being it could be one of a number of different types of rights.

What Are Rights?

We talk about the concept of rights as though they were something solid and defined. However, there is a great deal of disagreement about what a right is and what having a right entails. To begin with, there are a number of different types of rights. For instance, adopting the position of Wesley Hohfeld, a professor of jurisprudence, whose views are widely discussed within the legal philosophy community, there are claim-rights, immunity-rights, power-rights and privileges.11 Claim-rights are the rights I will be focused on here; they require the correlative duties of others for their fulfilment. Immunity-rights, on the other hand, provide their holder with freedom from the authority of others, such as freedom from tyranny12 and this does not fit with the type of right I am discussing. Neither does power-rights, which provide the holder with authority; for example, an employer has the right to order an employee to do his job. So too with privileges, which provide the holder with the choice to either do an action or to abstain from doing an action.13

Based on Hohfeld’s description of rights, the right in Article 7 of the CRC is clearly a claim-right, as opposed to the other rights cited above. Claim-rights necessarily comprise duty-holders on the Hohfeld account of rights.14 That is, where there is a claim-right, someone else has a duty to fulfil the right for the right-holder. In addition, if the philosopher James Nickel is correct, claim-rights also include scopes. For, according to Nickel, in Making Sense of Human Rights, claim-rights necessarily include:

11 Hohfeld, Wesley, 1920, p. 36.
13 Ibid.
14 Hohfeld, Wesley, 1920, p. 5.
Rightholders (the people who have them); addressees (parties assigned duties or responsibilities); and scopes that focus on a freedom, protection, or benefit. Further, rights are mandatory in the sense that some behaviors of the addressees are required or forbidden.¹⁵

As Nickel and Hohfeld point out, claim-rights require at least two parties for the right to exist—the right-holder and the duty-holder (the addressee), with Nickel recognising the importance of the scope of the right and the mandatory nature of rights. In addition, the philosopher Carl Wellman, in An Approach to Rights, argues that there is also a third party—the one appealed to when conflict occurs.¹⁶ In the case of Article 7 of the CRC, I hold that the child is the right-holder. Addressees and scopes I consider shortly. In the case of the CRC, the third party in cases of conflict is the Human Rights Commissioner.¹⁷ (I return to the issue of the CRC in the following chapter).

According to Nickel’s view, a claim-right is an entitlement to some freedom, protection or benefit that can be enforced by law or society. This view is generally uncontested and it is helpful here because the claim-right that I am discussing is, I will argue in chapter 3, a benefit to the right-holder. Nickel further points out that there are positive and negative rights; positive rights require the addressee to take some positive action, while negative rights require the addressee to refrain from doing something.¹⁸ It seems, therefore, that Article 7 of the CRC is a positive claim-right because it requires the addressee (duty-holder) to take action, that is, to provide the child (right-holder) with certain information about her genetic parents. However, some may claim that positive claim-rights are not so plausibly protected rights. I disagree. Many of the rights we take for granted are positive claim-rights. For instance, the right to an education is a positive claim-right. Children in Australia have the right to an education. This means that their parents and the state are required to take some positive action to educate them. This is generally achieved either by parents sending them to school or by ensuring that they are home-schooled and by the government providing the educators and school for children to attend. The positive claim-right to an education can be plausibly defended, I hold, on the ground that we want our children to be able to participate in, and become functioning members of society. This would be more difficult for an uneducated person to achieve, since most employers require potential employees to have at least the rudiments of an education. I also hold that the right to an education can be further

¹⁵ Nickel, James, 2007, p. 9.
¹⁸ Nickel, James, 2007, p. 23.
plausibly defended on the grounds that it is generally well accepted that a country whose citizens are lacking in education do not fare as well as countries whose citizens are better educated. Thus there are benefits to children and the state in protecting the right of the child to an education and risks of possible harms to children and state if children are not educated. As a result, ensuring children are educated has become a matter of law with penalties imposed on parents for failing to do so. Thus every child in Australia has a positive claim-right to an education that can be and is defensible. There are other examples, of course, such as our right to vote. Voting is a positive claim-right because citizens (as right-holders) must take some action to elect their representatives into office. The government (as addressees of this right) must provide the representatives, the polling booths and the ballot papers and so on in order that elections can take place. Society, as we know it here in Australia, would have to change drastically for this positive claim-right to be left without a plausible defence. This is because democracy is fundamentally dependent on the right of citizens to elect those they want representing them. This would suggest to me that some positive claim-rights can be plausibly defended. Of course, protection of positive claim-rights is dependent on whether or not they are enacted into law and whether or not penalties are instituted for abuses against them. Where they are instituted into law, they become protected positive claim-rights—in much the same way that the right to an education and the right to vote are legally protected positive claim-rights. The positive claim-right I raise here, I argue, can be defended on a number of grounds, which I present in the coming chapters. As a result, I will argue that the right expressed in Article 7 of the CRC should be enforced by law in order to protect the interests of the right-holders.

Having established the type of right I am discussing (a human right that is a positive, claim-right, which necessarily includes a duty-holder to fulfil the right, has a scope and a body of appeal in case of conflict), I now move on to conventional rights theories in order to establish my basis for children having rights.

**Rights Theories**

While there are a number of rights theories in current philosophical debate, the two most popular are the Will Theory and the Interest Theory. On one of these views (Interest Theory), children can be accorded rights. However, on the other (Will Theory), children are thought not to have any rights at all. This is because the Interest Theory grants that all those with interests have rights, while the Will Theory holds that rights are solely the domain of those who can exercise their will and make choices. So, although both sides agree that we ought to
protect children from exploitation and harm, Will Theorists argue that rights are not the only or even the best means of doing this.

**The Will Theory**

The philosopher Hillel Steiner, an advocate of the Will Theory, explains why children lack rights in *A Debate Over Rights*. He states, “The Will Theory contends that all powers pertaining to a duty must lie with the claim-holder, if he or she is to be a right-holder.”\(^{19}\) This means, according to Will Theorists, that someone has a right only if she herself has the power to claim or waive fulfilment of the duties imposed on others by her right. Rights cannot be held in proxy, that is, by others than the right-holder. Thus those that are dependent on others, such as infants, young children and the infirm, for instance, cannot have rights on this account of rights. This is one of the demands of the Will Theory, but it is not the only criterion necessary to have a right on this account.

The Will Theory also requires the right-holder to have the cognitive ability to make choices. A right-holder ought to be able to make informed decisions and he or she must have the freedom and control to exercise his or her will. Consider a person’s right to vote, for instance. In countries where people have a right to vote, the voter should be able to make an uncoerced and informed choice between candidates. The voter must have the ability to choose his preferred candidate himself; a proxy vote will not suffice. Furthermore, the voter must have the power or will to claim his right to vote. Whether the voter chooses to exercise his right to vote or not, he must be able to make that choice, if he is to qualify as a right-holder on the Will Theory view. Again, young children cannot fit easily into this account of rights.

Furthermore, Will Theorist Carl Wellman argues that “The essential function of any right as a whole is to confer autonomy, freedom and control, over some defining core upon the right-holder.”\(^{20}\) Wellman continues, “Because infants lack the psychological capacities necessary for choosing and acting freely or exercising control, it is both pointless and misleading to ascribe rights to them.”\(^{21}\) Once more, the Will Theorists challenge to children’s rights, at least regarding young children having rights, seems convincing.

Others such as Robert Goodin and Diane Gibson, in *Rights, Young and Old*, are concerned, not that children in general are unable to be included among right-holders, but

\(^{19}\) Steiner, Hillel, in Kramer, Matthew et al., 2000, p. 245.
\(^{20}\) Wellman, Carl, 2010, p. 17.
\(^{21}\) Ibid.
rather that very young children and “the mentally infirm old” are unable to indicate what their preferences/interests would be and this decision would be left to their carers to intuitively work out. Because the very young and ‘mentally infirm old’ are unable to clearly state their interests, they are in much the same position as those not cognizant or morally responsible enough to make choices on the Will Theory. As a consequence, infants and “seriously incapacitated dementia victims” would also fall outside the criteria for being right-holders on the Will Theory account of rights. This would be problematic for my thesis if I were arguing that the information about genetic parents should be provided to infants and the very young. Naturally, I do not make that claim; for the information given at this stage of life would be of little use to them.

Clearly Will Theorists have an obvious problem with ascribing rights to young children, especially infants. On Wellman’s account of rights, to grant rights to children would be to regard them as having freedom and control over some factors in their lives. Of course, many children, especially the very young, do not have the capacity to be independent in this way. However, this is not true of all children. Some older children may indeed have freedom and control over some factors of their lives.

However, when considering the Will Theory account of rights, we discover that there is another element to the debate on children’s rights that prevents children from having rights and that is in regards to moral responsibility. Carl Wellman argues,

The microargument assumes that among the elements in any genuine right must be at least one liberty and one power. Because to possess a moral liberty is to be morally permitted to act in some specific manner and to possess a moral power is to have the ability to bring about some specific moral consequence by one’s action, only a being capable of acting in the morally relevant sense could be said to possess either of these essential constituents in any right.

Because a right confers liberty on, and recognises power in, a right-holder, it is important that a right-holder be morally responsible for his actions. However, children are not always capable of acting in the morally relevant way that is required to have the power and liberty conferred by a right. Thus, we cannot grant children independence or permit young children to act as they choose because the consequences of their actions may not be morally or legally permissible. And, since very young children do not comprehend the consequences of their actions, we cannot hold them accountable for them. Giving very young children the liberty

---

24 Ibid., pp. 17-18.
and power to vote in an election campaign, for example, would be to place more responsibility on them than they are able to cognitively or morally handle. Thus, we rarely demand morality from very young children. In general, children are simply not autonomous enough in the way that is required to exercise rights. Therefore, on the Will Theory account of rights, it seems meaningless to think in terms of children having rights.

However, it is possible that a child could develop the moral accountability and cognizance required to be a rights-holder well before adulthood. The issue is that some dependent others, for example infants, do not have the capacity to be independent in the way that rights require. All we can really say about children is that at some point in their maturing lives they will have the necessary qualities to be right-holders, but we cannot say with any certainty when this will be. It may be different for each child and it would be quite impractical to regularly test every child so as to determine if they qualified to be a rights-holder. Thus, rather than risk giving children rights prematurely, it is thought better to withhold their rights until they have reached the legally accepted age of adulthood. The conclusions drawn by Will Theorists are that it is better not to talk in terms of rights when it comes to certain individuals, including children.

This is an unfortunate outcome for my thesis and the Will Theory, because it denies that some people can possess rights, including children. Because it does not allow that all citizens can have rights, Hillel Steiner in *Working Rights* reasons, there will always be fewer Will Theory right-holders than actual citizens. He argues,

> In *any* world, there are going to be far fewer Will Theory right-holders than Interest Theory right-holders. For the set of creatures who are capable of exercising powers can never amount to more than a very small subset of the creatures who have interests, however interests are construed. Hence foetuses, minors, the comatose, the mentally disabled, and also (as I have argued elsewhere) the dead and members of future generations—to say nothing of members of virtually all other known species—must all lack Will Theory rights.25

Clearly, from the perspective of the Will Theory, not everyone can have rights. Rights are only held by those with the power to exercise their will or choice in a way that expresses moral responsibility and includes the ability to state one’s important interests that require protecting by rights claims. Young children and certain others do not have this sort of power and ability. Therefore, quite a number of people, including children, are without rights on the Will Theory account of rights. This means of course, that children could not have the rights in the CRC, including the right expressed in Article 7. Thus, their important interests, along

---

with the important interests of others who do not qualify as rightholders on the Will Theory account of rights, would appear to be unprotected.

**Solutions To Counteract The Problem Of Children's Lack Of Rights On The Will Theory Account**

Naturally, even though the Will Theory does not attribute rights to those who are unable to claim them, those who hold this view do not believe that other persons may harm those without rights at will. Rather, as we will see, Will Theorists search for different concepts to express the moral requirements that other persons have towards dependent others, such as children. No one denies that children, like adults, have interests that ought to be protected. What is being debated in rights-theory discourse is the best norms or concepts to use in expressing this need for protection of their important interests. Simply put, Will Theorists deny that a rights-based approach is the best method for protecting children’s important interests. As a result, a number of philosophers have tried to circumvent the problems of according children rights with different solutions to the problem.

One solution to the problem of children failing to have rights on the Will Theory account is offered by the philosopher Onora O’Neill, a defender of the Will Theory, in *Children’s Rights and Children’s Lives*, who speaks of our duties and obligations to children. O’Neill argues that, when it comes to children, rather than rights, it is better to speak in terms of the obligations that we owe to them:

> I conclude that taking rights as fundamental in ethical deliberation about children has neither theoretical nor political advantages and suggest how we could obtain a more direct, perspicuous and complete view of ethical aspects of children’s lives by taking obligations as fundamental.26

O’Neill claims that “To speak of rights for children, can only be an indirect way of reminding people of their duties towards them.”27 She argues that we should abandon talk of rights-based approaches and replace them with a duties-based approach instead.28 O’Neill suggests that rather that thinking in terms of children’s rights we should think instead in terms of the obligations we have to children.29 Thus on O’Neill’s account, the norms for protecting children’s important interests should be thought of in terms of our duties and obligations to them. O’Neill’s proposal has the advantage of recognising that children have interests that

---

27 Ibid., p. 15.
28 Ibid.
29 Ibid., pp. 24–5.
need protecting and it places fundamental obligations on adults to protect those interests. However, as we will shortly see, there are problems with this solution.

Of course, O’Neill’s is not the only solution put forward to counteract the problem of children not possessing rights on the Will Theory account of rights. Goodin and Gibson argue that “A much more apt description of our duties and their due is couched in terms of a broader but in many ways more demanding notion of ‘right conduct’ toward dependent others.”30 From Goodin’s and Gibson’s perspective, it is more appropriate when referring to children, for instance, to speak in terms of our ‘right conduct’ towards them,31 while O’Neill speaks in terms of our ‘obligations’ to them. These are just a couple of the solutions that have been put forward to rescue children’s rights from the constraints of the Will Theory and there is no denying that where the Will Theory prevails, it is better that children are protected in other ways against abuses of their interests.

**Problems With These Solutions**

However, even though they may be helpful, there may be something lost by adopting the approaches laid out by O’Neill and Goodin and Gibson to help counteract children’s lack of rights. For instance, referring to ‘right conduct towards children’ and our ‘obligations’ to them may only have rhetorical force rather than the force that is necessary to fully protect their interests. These claims on obligations and right conduct may not have the force that claims on rights do. For instance, people may not be as convinced about their duties and obligations to children and what is the ‘right’ behaviour towards them as they may be by the forcefulness of rights talk. People may be inclined to shirk their duties and obligations to children because children are vulnerable individuals and people can take advantage of them when their own interests are thought more important. Thus they may not be as convinced by demands of obligations and right conduct towards them as they would be by right’s talk.

On the other hand, if those obligations and right conducts were enforced by law, then they may have all the force behind them necessary to protect children’s interests from abuse, in the same way that a right that was enacted into law to do the same thing would. Yet, even despite this provision, there still appears to be something lost by taking these approaches. For rights appear to have a strong universal force when it comes to protecting people’s fundamental interests that other claims on individuals do not. This is especially true when

30 Goodin, Robert & Gibson, Diane, 1997, p. 185.
31 Ibid, p. 201.
those rights have also been made into laws in their jurisdictions. There appears to be a number of benefits to addressing protections in the form of rights that right conduct and obligation based approaches lack.

**Benefits Of Talking In Terms Of Rights**

Indeed, there are good reasons for thinking that the concept of rights expresses the moral requirement to protect children’s interests better than alternative moral concepts. For example, rights are a familiar and popular concept. People understand the concept of rights, even if they have no philosophical conception of them. They know that rights entail that other parties (addressees) have corresponding duties towards the right-holders. They know that they can appeal to authorities when (what they regard as) their rights have been breached or they believe they ought not to be duty bound to the right-holder. This is in addition to the laws that may be enacted to protect rights, such as those imposed by the Australian Human Rights Commission. Rights can reflect a sense of substance and security for people because there are a number of avenues of appeal.

Furthermore, rights can create a sense of unity among people seeking the same goal. For instance, people have a propensity to mobilise and demonstrate against what they consider to be rights abuses. This can be an effective tool because, in many cases, such demonstrations can put pressure on legislators to change public policy in favour of more equitable laws. People may choose this method of appeal because they believe rights protect their interests better than other norms that may do the same thing.

If people adhere to norms that are expressed as right-claims better than they do to norms that are expressed in other terms, then this would be a good practical reason for favouring the terminology of rights. The many instances of change to social norms that have been brought about by claim-rights seem to lend support to the idea that rights-claims gain greater adherence than other claims. For instance, following equal opportunity for women in employment (a claim-right gained after many years of protests and demonstrations), employers in Australia can no longer discriminate against a potential employee based on gender. This right, places a duty on the employer to be objective when it comes to employment. Stated in the form of a right puts greater pressure on employer’s to do the right thing or risk the consequences of incurring penalties imposed by the Equal Employment Opportunity (EEO) tribunal.

Children’s interests too are better protected because of rights-claims. For instance, they now have a right that protects their interest to an education and a right to freedom from abuse,
interests they may not have had protected without the forcefulness of these rights-claims. When we think that it was not that long ago that young children were expected to work to support themselves and their families, many working in mines in appalling conditions. These protected interests in an education and leading a life free from abuse have brought vast improvements to their lives. Although these rights are also laws, the recognition of them as rights adds force to their adherence. Indeed, it may have been the arguments for a moral basis for educating children that brought about the right to an education for all children in the first instance. This may have subsequently led to the institution of this right into law.

Whether this was the case of not, the concept of rights is universally understood. Many countries have instituted human rights norms and work to ensure that those rights are protected in law. As they are so important a factor in protecting people’s welfare and fundamental interests, human rights are monitored by the United Nations, which can investigate and publicly report rights breaches. The United Nations has two main bodies to promote and protect human rights—charter bodies and the Human Rights Council. Charter bodies “are established under the UN Charter in order to fulfil the UN’s general purpose of promoting human rights. They have broad mandates that cover promoting human rights in all UN member states.” However, this is not the principle body responsible to the UN.

The principal UN Charter Body responsible for human rights is the Human Rights Council (HRC). The General Assembly established the HRC in 2006. One of its main purposes is to review the human rights record of every UN member state once every four years and to make recommendations for improvement. The United Nations can also make recommendations “about how the State Party can improve its compliance with its treaty obligations.”

When there is conflict over human rights in Australia, the party of appeal is the Australian Human Rights Commission. So, having the rights in the CRC mean that children in Australia have an avenue of appeal open to them should they wish to challenge the current norms regarding information about their genetic parents. It may be because there are such recognisable global mechanisms in place that rights have such a wide appeal. However, if children do not have rights, as Will Theorist argue, then they would lose these avenues of appeal when their important interests were ignored or abused.

---

33 Ibid.
34 Ibid., p. 1.
35 Ibid.
36 Ibid., p. 2.
Criticism Of The Will Theory

Therefore, it could be argued that since the Will Theory cannot account for what is owed to children and dependent others in the form of rights that it is not the best theory of rights. The fact that the Will Theory cannot capture all persons within its scope makes it an exclusionary theory, thus making it less encompassing than one would like a moral rights theory to be. If the concept of rights is useful in a normative sense and widely accepted, then a rights theory would be more appealing if it could be more generally applied.

Children could have rights despite their lack of cognitive capacities, if the protection of those rights could be handled by other parties, such as institutions. In such a case, there would be no reason to think in terms of children not having rights, or even requiring cognitive abilities. Even O’Neill concedes that just because children “cannot claim their rights for themselves, this is no reason for denying them rights.”38 “Rather”, she argues, “it is reason for setting up institutions that can monitor those who have children in their charge and intervene to enforce rights.”39

Under such circumstances, it would not be necessary for right-holders to have the cognitive power themselves to claim rights and to make choices that are capable of expressing moral responsibility, since institutions could be established to do this on their behalf. This would allow any duties or obligations imposed by children’s rights to be legally enforced by state institutions. Indeed, the state has set up institutions that step in to ensure that the obligatory behaviour by adults towards children is enforced. The Department of Community Services (DoCS), for instance, was instituted to protect children from abusive parents. DoCS can remove children from abusive homes for their protection, sometimes against the parents’ wishes. So, in reality, institutions can be set up to enforce children’s rights, while apparently still allowing children to remain the right-holders. However, Tom Campbell argues in The Rights of the Minor: As Person, as Child, as Juvenile, as Future Adult that, in effect, this amounts to proxies having the right, because it is they “who possess the power which is said to constitute the right.”40 If Campbell is right, this would bring us back to the view that children cannot have rights on the Will Theory account of rights because they cannot claim or enforce rights claims themselves since they lack the cognitive ability and power to do so. As a result of its demanding criteria, the Will Theory lacks the

39 Ibid.
40 Campbell, Tom, 1992, p. 4.
capacity to include young children and dependent others among right holders because of their lack of cognitive and autonomous abilities. This theory of rights is, therefore, not universally applicable across all human beings. Therefore, there is reason to resist the Will Theory as an appropriate starting point for this thesis.

**The Interest Theory**

On the other hand, a normative theory that can incorporate more human beings within its scope would be a more acceptable normative theory, in my view, than one that can only cover a lesser number. Given that the Will Theory cannot account for children’s rights, a rights theory that can would seem to be more acceptable than the Will Theory. Therefore, another reason for my resistance to the Will Theory is that there are other views in the rights debate that can account for children having rights. This takes us to the Interest Theory, a theory that can acknowledge children’s rights.

The Interest Theory bases rights on interests: those human beings with (certain) interests (to be identified by the theory) have rights. This is in contrast to rights being based on cognitive ability and autonomy. The concept of rights being based on interests rather than cognitive ability and autonomy is consistent with the idea of children having rights. The Interest Theory accords rights to those, including children, who have legitimate, important interests. Campbell argues, “According to this—the interest—theory of rights, children have rights if their interests are the basis for having rules which require others to behave in certain ways with respect to these interests.”41 Furthermore, if having interests is a sufficient basis for having rights, then children have rights if they have interests. In addition, if their interests were a sufficient basis for the rights enumerated in the CRC, then children would have those particular rights. Goodin and Gibson explain further:

> On the Interest Theory, what rights protect is not so much choices as interests. On that account, it does not matter that right-holders are not in a position to assert rights—or, indeed, even to conceptualize them as rights capable of being exercised. All that matters on this Interest Theory of rights is that right-holders have interests to be protected by such rights.42

This means that rights, on the Interest Theory, are not based on people having the power to exercise their wills or choices, as they are on the Will Theory, it is based on those with interests. As Goodin and Gibson explain:

---

41 Ibid, p. 5.
42 Goodin, Robert & Gibson, Diane, 1997, p. 188.
There is no need, on the Interest Theory, for right-holders to possess an autonomous will or to be capable of exercising reasoned choices. All that is required in order for people to be fit subjects for the ascription of rights is for them to have recognisable interests.\(^{43}\)

Unlike the Will Theory, the Interest Theory can include young children and independent others because it accords rights on the basis of interests. As Goodin and Gibson points out, “Everyone—young or old, sane or senile—has interests capable of being protected in this way.”\(^{44}\) This highlights the advantage of the Interest Theory in so far as it is a more inclusive theory than the Will Theory, including many that the Will Theory must necessarily omit, such as children.

Ascribing rights to children does not entail that children are equal to adults. Children have different rights, such as those enumerated in the CRC, in most if not all jurisdictions. Nevertheless, a person has a right, according to the Interest Theory, not because she can make choices, but because she has important interests that ought to be protected. In this way, the Interest Theory is able to include all persons within its scope, which is an advantage for a normative theory of rights, where we would wish to include as many individuals as possible. It is because the Interest Theory is more inclusive than the Will Theory that I accept it here with only brief discussion, for the purposes of moving discussion along.

**Criticism Of The Interest Theory**

Of course, this does not mean that there are not problems with the Interest Theory. Despite its advantages for children’s rights, like the Will Theory, some criticism has been levelled at this theory also. One of the main objections to the Interest Theory of rights is that because it is based on interests, in the case of children, for instance, we are simply making assumptions about what their interests are or what they will be in the future. This was the problem raised earlier by Goodin and Gibson. As a consequence, the assumptions we make about their interests (be they our own or another’s for the present or into the future) could be mistaken. More precisely, as Campbell points out, “It may be a weakness of the interest theory of rights … that it leaves us with a very open ended basis for determining which interests are to serve as the ground of rights.”\(^{45}\) The Interest Theory thus has the task of specifying which interests ought to be construed as rights, as has been pointed out by Joseph Raz in *Morality of*

---

\(^{43}\) Ibid.

\(^{44}\) Ibid.

\(^{45}\) Campbell, Tom, 1992, p. 16.
This is a challenge for the Interest Theory. For, how can we know what children’s fundamental interests are and what they will be in the future? On this point, we can only make assumptions and we could be wrong.

**A Response To This Criticism**

Granted, any interests children might have are based on our potentially incorrect assumed understandings of their current and potential future desires. However, the Interest Theory can accommodate changing conceptions of interests. If children who mature to the point of being able to reflect on their rights were to identify interests that differ from what had been protected for them by previous rights norms, these new choices could also be incorporated into the rights norms that are actually accepted and enforced for young children. (In this respect, of course, the Interest Theory has no advantage over the Will Theory, which can also accommodate changing conceptions of what is to be protected by rights norms.)

Nonetheless, we can make some assumptions about what children’s interests should be protected by rights. Thus, apart from what maturing children might inform us about their interests, we can also make some very plausible assumptions about younger children’s fundamental interests. Although we may be mistaken in some cases, it is plausible to think that children have interests in staying alive and keeping healthy. Although they may reject the notion when they are young that their interest in an education ought to be protected in the form of a right, it is assumed that they will appreciate the protection of this interest when they mature and see the advantages that this right bestows when competing for jobs, for instance. There are also good reasons to think that children have or will have an interest in knowing something about their genetic families. Protecting their interests is a prime objective of the Interest Theory and the CRC. I will defend in Chapter 3 the claim that the interest in knowing something about one’s genetic family is sufficiently important to warrant rights protection.

The inability of the Will Theory to account for children having rights has led me to reject this theory of rights. While it is recognised that discussion on rights theories has been brief and, in particular, criticism of the Will Theory, the inclusion of this chapter was to provide a starting point from which to discuss the finer details of the issue at hand, namely, whether or not children should have the right expressed in Article 7 of the CRC, that is, the right to know the identities of their genetic parents. Therefore, for the purposes of this thesis, I accept the

---

Interest Theory of rights and begin my position from this perspective in order to move on to further discussion on the issue at hand.

**Conclusion**

The Will Theory forces us to seek an account of our moral obligations towards children that is not rights-based, but rather is based on some other normative concept. The Interest Theory, by contrast, construes moral obligations towards children in terms of children having rights grounded on their important interests. As providing a full philosophical defence of one of these theories is not the main point of my thesis, I adopt from here on out the concept of rights as an adequate means of expressing what adults owe to children. Although sometimes vague, the discourse of rights helps to focus on the wellbeing of children. Since the Will Theory does not allow for young children having rights, the Interest Theory is being accepted here as my starting point and as my understanding of the nature and foundation of human rights, including the children’s rights enumerated in the CRC. In the next chapter, I turn to the CRC itself and the right expressed in Article 7, in which I discuss the most appropriate rights treaty to adopt in order to protect children’s important interests under the Interest Theory account of rights.
2 The CRC Rights

Children have moral rights and ought to have legal rights on the Interest Theory account of rights. However, their rights ought to differ from adults’ rights because children differ from adults and have distinct interests and vulnerabilities needing special protection. To this end, the CRC was designed to promote the rights of children. It was originally adopted by the United Nations in 1989. It was ratified by Australia the following year. As testimony to its popularity, the CRC is the most widely adopted human rights treaty in the world and its compliance is monitored by the Committee on the Rights of the Child, which is a United Nations treaty body composed of 18 independent experts. Ratifying this agreement places an obligation on governments to uphold and enforce the rights it contains. Only two countries have yet to ratify it—Somalia and the United States. According to one CNN online news report, which I have no reason to doubt, Somalia is an unstable country (at this point in 2011) in the grip of warfare. This indicates to me that Somalia is, therefore, not currently in a position to adopt any treaties. The United States, on the other hand, has signed the CRC, indicating its intention to ratify the treaty, but is yet to follow through on ratification. Even without the United States and Somalia ratifying this convention, the rate of global acceptance of the CRC is extremely high. According to UNICEF, “More countries have ratified the Convention than any other human rights treaty in history.” This may be an indication of the importance people the world over place on the rights, fundamental interests and wellbeing of children.

Other Human Rights Treaties

In 1990, Australia became one of the first nations to ratify the CRC—a ratification that accorded children in Australia a great many socially recognised rights from that time on. Of course, children in Australia had human rights prior to the implementation of the CRC. Other treaties were in effect in Australia prior to that date, such as the Universal Declaration of Human Rights. This document, which was brought into effect in 1948, accorded rights to

---

50 Ibid.
51 CNN Wire Staff, 7/09/2010, np.
53 Department of Foreign Affairs and Trade, 1995, np.
54 Ibid.
everyone.\textsuperscript{55} Of course, some of the rights in the *Universal Declaration of Human Rights* are inappropriate for children. For instance, Article 23(1) states that “Everyone has the right to work, to free choice of employment, to just and favourable conditions of work, and to protections against unemployment.”\textsuperscript{56} This may well have been a proper right for children to have when they worked long hours in the coalmines of Newcastle during Victorian times, for instance, but our norms and values have changed and we no longer think it appropriate for young children to work in coalmines or, indeed, anywhere at all. Since within our current norms and values we think it inappropriate for children of a young age to work; this is an unsuitable right for children to have. As it did not take account of children and our current norms surrounding them, the *Universal Declaration of Human Rights* became an unsuitable right’s treaty for children.

As a result, the *Universal Declaration of Human Rights* was superseded (with regard to children) by the *Declaration of the Rights of the Child*, which was adopted by the United Nations in 1959.\textsuperscript{57} This declaration was better suited to children. For instance, it recognised in Principle 9 the interest children have in not having to work, which states—

\begin{quote}
The child shall be protected against all forms of neglect, cruelty and exploitation. He shall not be the subject of traffic, in any form. The child shall not be admitted to employment before an appropriate minimum age; he shall in no case be caused or permitted to engage in any occupation or employment which would prejudice his health or education, or interfere with his physical, mental or moral development.\textsuperscript{58}
\end{quote}

Clearly, this is more in keeping with today’s norms and children’s fundamental interest in not having to work than the right to employment as expressed in the *Universal Declaration of Human Rights*. However, despite its appropriateness for children, the *Declaration of the Rights of the Child* became an inefficient rights treaty for protecting the many important interests children have. It is a short document, outlining just ten very sketchy principles.\textsuperscript{59} It fails to mention, for instance, the right protecting children’s interest in “survival and development”, as is protected by Article 6(1) of the CRC, which holds, “State parties recognise that every child has the inherent right to life.”\textsuperscript{60} Clearly, this is an important interest children have, along with other members of the community. It also fails to mention children’s right to know about their genetic parents. This, of course, may have been due to

\begin{footnotes}
\item[55] Ibid.
\item[56] United Nations Organisation, nd, np.
\item[58] Hodgkin, Rachel & Newell, Peter, 2007, p. 718.
\item[60] Hodgkin, Rachel & Newell, Peter, 2007, p. 83.
\end{footnotes}
the lack of understanding at the time this document was drawn up regarding the affect on children of not having information about their genetic parents. (I come back to this issue in chapter 3). Nevertheless, the brevity of this document of rights was problematic because a document as short as the Declaration of the Rights of the Child would obviously fail to recognise a number of children’s important interests that many would agree need protecting, such as their right to life. Rights, it is generally accepted, protect important interests from exploitation and abuse. A document that protects more important interests is an improvement on a document that covers less of them.

This document was also noted to be sketchy. This may have been due to the fact that there were no explanations or definitions for its particular wording. This would leave room for misinterpretation or multiple interpretations. This is problematic when it comes to instituting legislation covering the rights this treaty contains. Thus, there were good reasons for instituting a convention of rights that was more substantial and that specifically applied to protecting a greater number of children’s important interests.

**Advantages Of The CRC For Children Over Preceding Rights Treaties**

Indeed, the CRC is an extensive treaty, containing over forty articles of rights and related material, which can be broken down into eight general categories. They are, according to human rights law professor, Jonathan Todres:

- general measures of implementation; the definition of the child; general principles (including non-discrimination, the best interests of the child, the right to life, survival and development, and respect for the views of the child); civil rights and freedoms; family environment and alternative care; basic health and welfare; education, leisure, and cultural activities; and special protection measures (including such areas as sexual exploitation of children, child labour, children in armed conflicts, and refugee children).61

The CRC seeks to protect more important interests of children than the Declaration of the Rights of the Child, which was an improvement (for children) on the Universal Declaration of Human Rights. The CRC is a document about liberties, health, and welfare—the liberty of freedom of speech (Article 12), the basics of health care (Article 24[1]), and adequate nutritious food (Article 24[2c]), to name but a few.62

These protections may appear a bit paternalistic to some, who may consider this one drawback to the interest theory. However, protecting children’s fundamental interests in the

---

62 Department of Foreign Affairs and Trade, 2007, np.
form of a rights treaty such as the CRC is one way to make sure that what is in their best interest is not ignored or forgotten. If the best way to protect children’s interests is in the form of a human rights treaty, then the CRC is, to date, the best suited treaty for this task. This is in light of the human rights treaties that preceded it, such as the *Universal Declaration of Human Rights* and the *Declaration of the Rights of the Child*, which were shown to be unsuitable and inadequate for protecting children’s important interests.

The rights in the CRC were established to protect children’s interests from exploitation and abuse in response to the inadequacies of the treaties that preceded it. Nonetheless, it has adopted some of the language and principles of the other treaties. Following the example of the *Declaration of the Rights of the Child* (Principle 2, “In the enactment of laws for this purpose, the best interests of the child shall be the paramount consideration.”)\(^63\), for instance, Article 3 of the CRC bases its rights on the “best interest of the child”:

> In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.\(^64\)

This was obviously seen as an importance principle as it grounds the other rights in the best interest of the child. As can be seen from Article 3, states are required to make children’s best interests of primary concern in legal, administrative and institutional matters. This important right had repercussions on family law. From the inception of the CRC, the family law courts in Australia have advanced the concept of the best interests of the child. According to the Family Law Courts “When a court is making a parenting order, the *Family Law Act* requires it to regard the best interests of the child as the most important consideration. Parents must also use this principle when making parenting plans.”\(^65\) Not only is the Family Law Courts required to do what is in the best interest of the child, but the *Family Law Act* also calls on parents to do what is in the best interest of the child. Without this legal consideration of children’s best interests, a number of children’s fundamental interests may well be ignored or forgotten, perhaps, resulting in detriment to some. This may explain the importance that the *Declaration of the Rights of the Child*, the CRC and the *Family Law Act* place on what is in the best interest of children rather than what is in the best interest of their parents and others. Here, too, it is to be noted that this is a positive claim-

---

\(^64\) Department of Foreign Affairs and Trade, 2007, np.
\(^65\) Family Law Courts, no date (nd), np.
right that has been plausible defended with such force that it has become a part of our legal system.

Since the rights treaties that went before the CRC were found to be lacking in some fundamental ways, the inclusion of more numerous fundamental interests of children makes the CRC an important vehicle for them to challenge abuses of their interests. The extensive nature of this document, outlining over 40 articles of right, makes the CRC a better vehicle to challenge abuses of children’s interests, because it can account for more of them than was previously possible with the two preceding documents of rights. Although we may not agree with each and every right it contains, the CRC, as we have seen, is more applicable to children, protects more of their interests and is in better keeping with the norms and values of today’s society than either of the declarations of rights that preceded it.

Furthermore, the CRC uses plain language that is readily understood by average people; one does not need to be an intellectual or legal professor to understand the articles of rights it contains. Another advantage to the CRC is that the rights it contains were written specifically with children as the right-holders. This is an obvious improvement on the *Universal Declaration of Human Rights*, which was written with everyone in mind, and contains many rights which are unsuitable for children in a number of ways. Given the number of advantages over preceding human rights treaties and because of its wider scope, it seems reasonable to think that the CRC is currently the best suited human rights treaty for protecting the important interests of children.

Of course, whether or not the implementation of all the rights in the CRC can bring about the best results in relations to children’s welfare and liberty (considered here to be important interests worth protecting in the form of rights) is beyond the scope of this work to evaluate. Instead, I contain my focus solely to one right—the right in Article 7(1).

**Criticism Of The CRC**

Notwithstanding its advantageous features, such as its wide scope protecting more interests, watchdog committee to monitor breaches of children’s rights, its popularity with people generally and its wide acceptance, the CRC is considered by some to be a controversial document. Many concerns have been raised about the rights it contains, even among some of the countries that have ratified it. In some cases, acting on the duties and obligations enumerated in the CRC’s articles of rights can lead to problems and dilemmas for both children and parents. I will raise some of these problems and dilemmas in later chapters in
this thesis. However, in this chapter I want to address some of the problems that have been raised concerning the language of the CRC.

One problem that has been noted with this treaty is the ambiguity of the language used in its articles of rights, in particular for my purposes Article 7—not stating the precise definition of parent is problematic. As previously stated, problems with misinterpretation and with meeting the standards of the CRC may arise because some of its terms are vague or ambiguous. This was a problem, as previously noted, with the Declaration of the Rights of the Child and one of the reasons for seeking an improvement in the form of the CRC.

A further problem that has been raised in relation to the CRC is that it is incomplete and has to be read along with other conventions and guidelines for a full understanding of its articles of rights. I will respond to these criticisms in turn, starting with the ambiguity of the terms used in the CRC articles.

**Criticism Regarding The Ambiguity Of The Terms Used In The CRC**

Of particular importance in the present context is the use of the term ‘parents’ in Article 7. This term is highly ambiguous, and the CRC does not specify which particular meaning is intended. There are many distinct types of parent, especially as a result of recent innovations in reproductive technology. For instance, there are foster parents, adoptive parents, donor parents, birth parents, surrogate parents, social parents and ‘natural’ or genetic parents. As a result, the word “parent” could refer to individuals who have either a very strong connection to the child or a very weak one. Again, as with the problems with the Declaration of the Rights of the Child, the lack of a clear definition for ‘parents’ leaves Article 7 open to multiple interpretations and misinterpretations. Again, this is problematic when it comes to instituting legislation surrounding this article of rights.

Article 7 does not refer specifically to genetic parents or to any genetic link between parents and children. On the other hand, neither does it reject genetic parents as those whom a child has a right to know. While it might be the case that children ought to know all of the persons who have a connection to them, it is knowledge of the identities of genetic parents that I defend in this thesis as a right of children. So, this is also a problem for my thesis, since it is necessary to have a clear understanding of what the CRC is advocating children should have as a right.

Even if the CRC used the words ‘biological’ and ‘birth’ when describing parents, the problem would remain. This is because the terms ‘biological parent’ and ‘birth parent’, when used in relation to mothers, could identify surrogate mothers. Birth mother is no longer
syndonymous with genetic mother. Today, the birth mother can be completely distinct from the genetic mother. This can occur, for instance, in cases where a woman has her eggs frozen prior to a hysterectomy. One of those eggs may later be fertilised by sperm, and the resulting embryo implanted into a surrogate mother who goes on to give birth to the child on behalf of the genetic mother. Therefore, even the terms ‘biological’ or ‘birth’ mother can refer to a non-genetic relationship between mother and child, as in the case of a surrogate mother. Such ambiguities could be an impediment to implementing laws that seek to promote the rights this treaty contains, including the right specified in Article 7.

Criticism Regarding The Incompleteness Of The CRC

Another criticism levelled at the CRC is that it is incomplete and has to be read along with other conventions and guidelines for a full understanding of its articles. One may, for instance, need to consult other treaties in order to gain some understanding of the basis for some of the rights in the CRC, such as the relationship between Principle 2 of the Declaration of the Rights of the Child and Article 3 of the CRC, as previously discussed. Of course, one could just accept the articles of the CRC without any reference to what went before. However, as previously stated, this leaves way for other interpretations than those intended to be drawn and legislators could misinterpret the articles of rights and make laws conducive to those misinterpretations rather than what the CRC intended.

The Implementation Handbook

On the other hand, guidelines, for a full understanding of the CRC would be helpful in gaining a better understanding of what the CRC actually intends by its Articles of rights and in particular for my purposes what it intends by Article 7. So it would be helpful to have some sort of guide, particularly for those expected to implement the laws to enforce the rights. Seeing this flaw with the CRC, an implementation handbook was developed under the guidance of UNICEF. It was in response to the criticisms noted above and in order to help governments and legislators implement the rights in the CRC that UNICEF developed the Implementation Handbook for the Convention on the Rights of the Child in 1998 as an aid to clarification of this treaty.66 According to the Executive Director of UNICEF, Ann Veneman, in her foreword to the Implementation Handbook for the Convention on the Rights of the Child (hereafter referred to as the handbook),

---

It has since become a well-known practical tool used by governments, UNICEF and other United Nations agencies, as well as non-governmental organizations, human rights institutions and academics, to guide them on the implementation of the Convention.\textsuperscript{67}

The handbook is an official set of guidelines produced in accordance with the CRC Committee.\textsuperscript{68} In addition to listing the articles of rights, the handbook also contains definitions of terms, explanations of the implications of each article and a number of criticisms that have been raised against countries that fail to address the rights breaches of their citizens. According to the handbook, the CRC Committee has criticised Uruguay, for instance, for failing to address the issue of children born out of wedlock, which has a tendency to lead to discrimination against some children in that country. The committee notes to Uruguay,

In this regard, the Committee is particularly concerned at the persisting discrimination against children born out of wedlock, including in regard to the enjoyment of their civil rights. It notes that the procedure for the determination of their name paves the way for their stigmatization and the impossibility of having access to their origins.\textsuperscript{69}

The CRC is concerned that children born out of wedlock in Uruguay may fail to carry their father’s surname, which may deny them access to part of their origins. As a result, children may be stigmatised as illegitimate and made to feel unequal to their peers. This statement to Uruguay not only indicates the way the CRC Committee scrutinises rights abuses worldwide, but it also shows a clear indication of the concern the CRC has for children to be able to access their genetic history (their origins).

As a result of the vast amount of information it contains on children’s rights problems around the world; the handbook is a good source of information about the rights in the CRC and how to implement them. According to the book’s authors, Rachel Hodgkin and Peter Newell, both children’s rights advocates, the handbook is “a well-known practical tool used by governments, UNICEF, and other United Nations agencies, as well as non-governmental organisations to help them in the implementation of the CRC.”\textsuperscript{70}

The handbook is also a source for legal inquiry into alleged cases of child abuse. As such, it has been extensively cited by the Australian Human Rights Commissioner throughout his report \textit{A Last Resort: A National Inquiry into Children in Immigration Detention}\textsuperscript{71} (2004).

\textsuperscript{67} Ibid.
\textsuperscript{68} Ibid., p. xiii.
\textsuperscript{69} Ibid., p. 102.
\textsuperscript{70} Ibid., p. xi.
\textsuperscript{71} Australian Human Rights and Equal Opportunity Commission, 2004, p. 102, 4.4.3.
Rights abusers can be held accountable for their actions, and, according to Article 19(1), states have a duty to protect children from breaches of their rights:

States Parties shall take all appropriate legislative, administrative, social and educational measures to protect the child 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.  

Where a breach of human rights has been found, the Australian Human Rights Commission furnishes a report to the Attorney-General, who then tables the findings in parliament, which can result in legislative changes. Therefore, in addition to being an additional source of information about the rights in the CRC and how to interpret them (I address this issue shortly), the handbook is also a good guide for governments and legislators, since it can be cited to hold rights abusers accountable and to change legal policies.

Furthermore, although it is not politically authoritative, the handbook is reliable, having been developed by UNICEF as a tool to understanding the articles in the CRC. The Committee on the Rights of the Child recommends the handbook, as it “provides a detailed reference for the implementation of law, policy and practice to promote and protect the rights of children.” The handbook has the support of the Committee overseeing the CRC and, therefore, it is a credible authority on the articles of rights in the CRC and it is an important guide for policy and legal proceedings. This makes the handbook a good source of information for the legal profession and legislators alike, because it fills an important gap between the CRC and its implementation. Thus the criticism levelled against the CRC on the grounds of it needing guidelines to comprehend its rights, may be accurate. However, the CRC has ensured a comprehensive guide is available to assist those who need further information and guidance. Because it is such a useful tool to guide one through the rights in the CRC, I refer to the handbook in response to further criticisms of the CRC, one of which is the terms used in the CRC.

The Handbook’s Explanation Of Terms Used In Article 7 Of The CRC

The handbook helps to clarify the terms used in the CRC. One of the most ambiguous terms in Article 7 of the CRC is ‘parent’, for this can refer to a number of individuals, as previously noted. However, and most importantly for my purposes, the authors of the handbook claim

---

that the word ‘parents’ in Article 7 includes first and foremost genetic parents.\footnote{Ibid., p. 105.} Thus, when Article 7 refers to ‘parents’, the handbook interprets this article as stating that children should have a right to know their genetic parents in the first instance.

According to the handbook, the CRC ascribes to children a right to know their birth parents and social parents along with their genetic parents. Thus the handbook states,

\begin{quote}
\text{as far as the child’s right to know his or her parents is concerned, the definition of “parents” includes genetic parent (for medical reasons alone this knowledge is of increasing importance to the child) and birth parents, this is the mother who gave birth and the father who claimed paternity through partnership with the mother at the time of birth (or whatever the social definition of father is within the culture: the point being that such social definitions are important to children in terms of their identity).}
\end{quote} \footnote{Ibid., pp. 105-106.}

While the CRC prefers that children know all those parents associated with their births, it includes most directly the right to information about genetic parents. It is because the handbook makes particular reference to the importance of information about genetic parents for health reasons that I understand the CRC to include genetic parents as a right of Article 7. Because the right to information about social and ‘birth’ parents is outside the scope of this thesis, I refrain from discussing these issues here.

However, the right in Article 7 is qualified with the words “as far as possible”. The handbook interprets this to mean that children should have this information where it is known.\footnote{Ibid., p. 97.} Information about some genetic parents may be largely unavailable because, for instance, the genetic father is unknown or the genetic parents are deceased or missing. Understandably, one cannot provide information that one does not have or that has never been recorded. Therefore, this qualification may prevent some children from realising their right as contained in Article 7. Barring this qualification, I understand the CRC to be advocating that if information is available on genetic parents then it ought to be made available to their children as a right.

As there is a qualification of the best interest of the child to consider along with the right in Article 7, there would be circumstances where it would not be in a child’s best interest to realise her full right to know and be cared for by her genetic parents. One of these circumstances is in making contact with genetic parents who posed a threat to the child. This qualification in Article 7 certainly would allow depriving the child of contact with parents

\footnotesize
\[\text{\footnotesize\text{\cite{Ibid., p. 105.}}}\]
who were considered dangerous, for instance, because of a concern for the best interests of the child.\textsuperscript{78}

However, because I am not arguing that children ought to be cared for by their genetic parents or even that they should have contact with those parents, I take these qualifications to mean that, in the best interest of the child, where information about genetic parents is known and can be made available to the child without harm to her, then it should be.

\textit{Who Is The Right-Holder And Addressee Of Article 7(1) Of The CRC}

There is another problem with the CRC regarding the discharge of the right in Article 7, if it were ever instituted into law. As previously stated, Article 7(1) of the CRC provides children with a right to know their genetic parents. It is children who have the rights accorded by the CRC, and, therefore, they are the right-holders addressed in this convention. On this matter there is little disagreement. However, the rights in the CRC are positive claim-rights. As a result, should a child (or someone acting on her behalf) claim her right to the fulfilment of Article 7, then a correlative duty must necessarily fall on an addressee to fulfil the child’s right, if Hohfeld’s argument about claim-rights, as previously stated, is to hold true and it clearly seems to in this case.

So, while it is clear who the right-holder (the child) is in this convention, it is not altogether clear who the addressee is. In the first instant, it appears that the convention is addressing governments. For, according to the United Nations International Children’s Emergency Fund (UNICEF), the CRC “reaffirms the notion of State accountability for the realization of human rights and the values of transparency and public scrutiny that are associated with it.”\textsuperscript{79} In the case of information about genetic parentage, however, the government may not have the information to pass on to the child unless it first obtains that information from the children’s genetic parents. This means that genetic parents would be required to provide that information to governments in order to allow the government to discharge this right. However, this would not get government far enough if genetic parents provided the information and others, such as social parents, for instance, decided to withhold the information from their children, thereby, denying children their right to this information. Therefore, it seems to me that the state, genetic and social parents, guardians and carers of the child, should all be considered as potential addressees of this particular children’s positive

\begin{footnotesize}
\begin{itemize}
\item \textsuperscript{78} Ibid., p. 109.
\item \textsuperscript{79} United Nations International Children’s Emergency Fund, 2006, np.
\end{itemize}
\end{footnotesize}
claim-right. I begin with the argument that the state is an addressee of Article 7 of the CRC in the first instance.

**Australian Government As Addressee Of The Right In Article 7**

Aside from the CRC identifying the State as addressee, the CRC is a United Nations human rights treaty that was signed by the Australian government over 20 years ago. This means that the Australian government has had plenty of time to consider or reconsider the rights this treaty contains. Since the government seems not to have come up with good reasons to reject the rights in this treaty in that time, then it seems reasonable to think that it accepts the legitimacy of the rights contained in this convention.

Furthermore, when a government ratifies a convention, it commits itself to that convention. According to UNICEF, “Having agreed to meet the standards in the Convention, governments are obligated to bring their legislation, policy and practice into accordance with the standards in the Convention; to transform the standards into reality for all children.” 80 Naturally, it is accepted that all rights have to be developed in conjunction with other, sometimes conflicting rights, and I address some of these conflicting rights in later chapters. However, having agreed to this convention and having had plenty of time to reconsider its position on children’s rights and Article 7, the Australian government ought to now ensure that Article 7 is not violated without good reason and that the necessary information about genetic parentage is passed on to Australian children. This is in view of their moral obligations to uphold the treaties they sign on to and in light of the fact that they have had plenty of time to reconsider their views regarding the CRC rights. Just because it is related to children’s rights, as opposed to adult rights, does not make the CRC any less significant or important a human rights treaty than other human rights treaties the government has ratified.

Where information about genetic parents is available, then governments that have ratified the CRC are obligated to ensure that the information is at some point provided to the relevant children. James Nickel quite rightly argues, “A country ratifying a UN human rights treaty agrees to respect and implement the rights the treaty covers. It also agrees to accept and respond to international scrutiny and criticism of its record.” 81 Beside adult human rights treaties, it is expected that Nickel’s statement would also refer to other human rights treaties that governments have ratified including children’s human rights treaties. I imagine this to be

---

80 Ibid.
81 Nickel, James, 2007, p. 15.
the case since Nickel is referring to our commitment and respect for human rights rather than the type of rights those treaties include. I imagine very few would argue that the type of person a human rights treaty protects should be a deciding factor in whether or not governments ought to, after ratifying a treaty, respect it. Since it is generally thought that governments should respect those treaties they ratify, including the CRC, this requires them to take steps to implement the rights in them. This, of course, would include the right in Article 7 of the CRC.

If the government are committed to respecting the treaties it is a signatory to, then having ratified the CRC, the government of Australia has committed itself to ensuring that children are protected by this treaty, including the right in Article 7. This is a contract between the Committee of the CRC and the Australian government (among other countries), with all the moral implications that the signing of a contract entails. Since a convention is a form of contract, it binds in the same way as any other contract agreed to and signed by consenting adults. Therefore, the government is contractually obligated to ensure that children have the rights in this treaty and, in particular for my purposes, the right enumerated in Article 7(1). By signing this treaty, as is the case with any treaty, a government commits to the contents of the treaty by the force of law, giving it the same moral force as enacting standard domestic legislation. Thus the Australian government are here considered addressees of Article 7 of the CRC, in the first instance.

**Parents As Addressees of The Right In Article 7**

One possible problem with this suggestion is that the government may not have the correct information—or, indeed, any information—to pass on to social parents in order that they can pass it on to their children. This can happen, for example, where records of gamete donors do not exist or where children have been ‘abandoned’. In such cases, children will be denied their rights to Article 7. However, where genetic parents can provide information for their children, it should be considered that they are also the addressees of the rights in this convention, and, therefore, should provide the required information about themselves.

Although not signing people up to specific laws, when governments sign treaties they do so on behalf of their citizens. Arguably, therefore, the Australian government has also committed its citizens, who include genetic and social parents, to this treaty. Since it is, generally speaking, genetic parents who have the relevant information, it is they who, it may be argued, are obligated in the second instance to pass that information on to their children via the children’s carers and social parents or a government institution that has been set up
for this purpose. It is argued, therefore, that genetic parents who have this information ought to, in accordance with the right in Article 7, pass it on to their children. Consequently, genetic parents are also to be considered as addressees of article 7 of the CRC.

One problem with this view, is that even if the genetic parents of an adoptee, for instance, provided information about themselves to the government, it would still require the social parents (those parents with the everyday care of the child, which could include adoptive parents, for instance) to pass it on to the child. This, of course, would then place an obligation on social parents and guardians to present this information to their children. Thus, social parent and guardians should also be considered as addressees of this right, in the third instance. So, even if the CRC identify the government as addressees of the right in Article 7, government cannot perform their duty without the cooperation of genetic parents and social parents.

Therefore, social parents, carers, and guardians should also be considered, along with government and genetic parents, as addressees of this right, since it is they who have the children in their care and it is generally only they who can directly pass on the information to their children. If it is accepted that children should have rights and the right contained in Article 7 of the CRC, then parents and guardians ought to ensure that their children’s rights are not abused, even if they would desire to do otherwise. As social parents stand in a particular relationship to the children in their care, information about their child’s genetic parents’ should come from them if the information is available to them. One good reason for thinking this way is that it would be better for this important information to come from someone the child trusts and feels close to, since this information could impact the child in an adverse way if not delivered with sensitivity to the child’s feelings and psychological welfare. Where a child does not have genetic parents to care for her, it ought to fall to the social parents, guardians or carers of the child to ensure that their child realises her rights, but in a caring and compassionate way. It is thought that this would be in the best interest of the child.

In essence what this means is that genetic parents would be required to pass information about themselves on, perhaps, through a government agency in order for that agency to pass it on to the child or her social parents, if she were a young child, who would then be required to pass it on to the child. This means that along with governments, and genetic and social parents, guardians and carers of children should also be considered addressees of the right in Article 7 of the CRC.

Of course, governments and social parents who do not have the information cannot be expected to provide it. Some adoptees, for instance, were ‘abandoned’ at birth with no
possibility of ever acquiring this information. Therefore, Article 7, even if it were obligatory by law, may not be able to be enforced where there is no available information about genetic parents. The same is true where genetic parents do not have this information available to them, as may be the case with mothers who do not know who fathered their children—rape cases may fit into this category, for instance.

Naturally, where parents do have the information and are not providing it, or they wish to conceal it from the child, this is problematic with regards to our committed respect for human rights and our commitment to honour the treaties we ratify. However, since it may be difficult for a child to obtain this information from social and genetic parents determined to withhold it from her, the onus should fall back on the state to legally enforce Article 7 of the CRC for the reasons mentioned above. (I discuss one way this may be accomplished in the chapter on mandatory DNA testing.)

Discussion On The Apportioning Of Obligations

A number of people may be required to act to discharge the right expressed in Article 7. For the government to honour its ratification of this convention it needs the cooperation of both genetic and social parents. It seems to me that the government, social and genetic parent of a child, at the very least, have a vital role to play in a child’s realisation of their right as expressed in Article 7 of the CRC.

Since the CRC is unclear on the precise details of this matter, some may contend that there would be problems with implementing this particular children’s right. However, clearly, the government have an obligation to uphold the treaties they sign on to. On the other hand, the government cannot ensure children have access to information about their genetic parents if the genetic parents refuse to provide it or they simply do not know. Furthermore, even if the government and the genetic parents complied with their obligations as addressees of Article 7 of the CRC, social parents would still be required, if they were counted as addressees, to discharge the information that the child is adopted or donor-conceived, for instance. However, it seems to me that instead of thinking that we cannot identify an addressee of this right, rather we can say that there are a number of addressees of this particular child’s right. At the very least, the government, based on its obligations as signatory, is an addressee of this treaty of rights in the first instance, genetic parents are addressees in the second instance and social parents are addressees in the third instance.
In Defence Of Addressing Rights In The Form Of A Convention Like The CRC

Despite its problems, there are advantages to addressing children’s human rights in the form of a convention like the CRC. For instance, as previously stated, the CRC seeks to promote the best interests of the child (Article 3). Of course, the Declaration on the Right of the Child also included this principle. However, this rights document failed to protect a number of their other interests via rights, such as a child’s right to life, as previously discussed. Again, although the CRC may seem incomplete, ambiguous and unclear at times, UNICEF has provided a handbook to assist with understanding and guidance with the implementation of the Articles of rights it contains.

Furthermore, the CRC not only provides understanding and guidance, but it also encourages stable and predictable patterns of behaviour through consistent monitoring. The CRC Committee can and does put pressure on signatories to its convention where it notes breaches to children’s rights. Furthermore, the Australian Human Rights Commissioner can act to change legislation when there are breaches to children’s rights in Australia. Thus, the CRC can be the basis for appeals to change legislation in order to better protect children’s rights. This is an advantage that appeals to right conduct and right behaviour lack, when not construed in the form of rights.

Moreover, since the CRC does not exclude any child, it may be assumed that the rights in the CRC apply to all children. This implies that, under the CRC, all children are to be treated equally in terms of having the same rights. As a result, the CRC can be considered an egalitarian treaty for its (child) right-holders. This means, for the purposes of this work, that the CRC does not draw distinctions between adoptees, donor-conceived children and other children, for instance.

In addition, as a treaty, the CRC identifies the rights children are entitled to in a simple list format, precisely naming the important concerns that are understood to be in the best interest of children the world over. This makes it easy for citizens, states, and legislatures to recognise the duties and obligations we have to children and to comply with CRC directives. In addition, the CRC’s list of rights provides a consistency that people and institutions can rely on. Knowing that there is a consistent list and knowing what that list consists of allows people to consider their options and make future plans. For instance, parents who know they are bound to adhere to Article 7 of the CRC have the opportunity to prepare in advance for the day their children would be informed of their genetic parentage. If parents were obligated

82 Department of Foreign Affairs and Trade, 2007, np.
to comply with a particular article of the CRC, they would know that the right in that article would not readily change at a moment’s notice. They could look at that particular right in the list in context with the other articles of rights. Having a consistent list of articles of rights provides people with the opportunity to prepare in advance for the day they are required to fulfil their obligations under particular articles.

Unlike the *Universal Declaration of Human Rights*, the CRC clearly takes into account the fact that children have distinct interests and vulnerabilities from adults. The lack of sufficient provisions to cover children’s interests left the *Universal Declaration of Human Rights* deficient and unsuitable for children. On the other hand, the *Declaration of the Rights of the Child*, like the CRC, was specifically designed with children in mind. However, the *Declaration of the Rights of the Child* is a document with few rights protecting few interests. Therefore, there was a need to introduce a more substantial document to account for the numerous important interests children have. This was achieved in the form of the CRC. The CRC is a more substantial document accounting for a greater number of rights. As more children’s rights protect more of their important interests, the CRC provides more protection for children than the *Declaration of the Rights of the Child* did.

While some of its terms are ambiguous, the CRC has the advantage of the support of the *Implementation Handbook* to help elucidate its content. This is something the *Declaration of the Rights of the Child* lacked. So, although there are ambiguous terms in the CRC and it may be incomplete, the handbook helps to complete it.

The handbook can also be a source of guidance to states and institutions on these matters and the implementation of the rights. At least one right in the CRC (Article 3) has led to the requirement in the *Family Law Act* that the Family Law Courts place children’s best interests as their primary concern. This Act also requires that parents do the same. Clearly, the rights in the CRC can impact the law, so it is an important means of protecting children’s interests in the form of rights.

Furthermore, the CRC has almost universal appeal and application, with most of the world ratifying this treaty in recognition of a need to protect the important interests of children. Taking all these qualities of the CRC into consideration, there are a number of good reasons for thinking that children’s interests are better served by the implementation of this convention than any treaties that preceded it.

Although it cannot provide an account of who the addressee is for Article 7, there are good reasons for thinking that there are a number of addressees to this right, including government and genetic and social parents. Aside from this absence of clarification of an
addressee for this particular right, there are still good reasons for thinking that the CRC is the best means of protecting children’s important interests in the form of rights and in particular the rights in the CRC, including their interest in knowing the identities of their genetic parents as expressed in the right in Article 7.

In Defence Of Addressing Rights In The Form Of A Convention Like The CRC

The rights in the CRC are binding not only on the Australian government, but also on the parents of children in Australia, due to the government’s ratification of it. In order for children to realise the rights in Article 7, it is necessary that Australian citizens support their government were it to enforce this right on behalf of Australia children. This is supported by the views of the philosopher John Stuart Mill who claimed,

When we call anything a person's right, we mean that he has a valid claim on society to protect him in the possession of it, either by the force of law, or by that of education and opinion. To have a right, then, is, I conceive, to have something which society ought to defend me in the possession of.83

If children have rights, which they do on the Interest Theory account of rights and, if Mill is correct, then citizens ought to defend children, as right-holders, in the possession of their rights. Since I argue that children have rights, then we should adhere to Mill’s argument. Of course, if Mill is wrong, I would still imagine we would want to protect children’s rights against abuse, simply because they are vulnerable members of society needing support in the establishment of their rights into laws. One way that citizens could ensure that children’s rights were established as laws is by acknowledging the importance of the rights in the CRC for children and by ensuring that the government does not fail in its duty to enforce the CRC’s articles of rights, including Article 7. According to the writers of the Implementation Handbook, “While it is the State which takes on obligations under the CRC, its task of implementation—of making reality of the human rights of children—needs to engage all sectors of society and, of course, children themselves.”84 In addition, according to the philosopher John Eekelaar in The Emergence of Children’s Rights, “It seems plausible that a child may expect society at large, no less than his parents, to ensure that he is no worse off than most other children in his opportunities to realize his life-chances.”85 If these views are right, then it would appear that we are all, as Australian citizens, responsible for ensuring that the Australian government do not fail in their enactment of the rights specified in the CRC.

---

83 Mill, John, Sturt, 1861, p. 54.
We can do this by acknowledging the importance of the interests these rights protect and by supporting government when it seeks to implement children’s rights.

However, even if the writers of the handbook and Eekelaar are wrong and people have no reason to support children’s rights, they should still support government’s ratification of international human rights treaties, because these treaties are intended for the benefit of citizens and seek to protect their fundamental interests. As previously stated, it should not matter that these are children’s rights and not adult’s rights in order for us to respect our government’s ratification of this treaty. This is also the case with the right articulated in Article 7 of the CRC. The only difference being that in this instance the right refers to children rather than adults. Children are citizens and the right in the CRC, including Article 7, were intended to protect these citizens’ fundamental interests and wellbeing.

In addition, people should support children’s rights because children are vulnerable and prone to harms through their dependence on others and because they are unable to defend their need for rights to protect their fundamental interests through their own cognisant powers. As children are unable to protect their own rights and fundamental interests, they may come to harm and may fail to flourish in the way that they would if their fundamental interests were protected. Therefore, people should support the CRC because it seeks to protect children’s fundamental interests and wellbeing by seeking to prevent harms to them and by ensuring that they are not disadvantaged in relation to most other citizens in regards to certain goods. As most children know the identities of their genetic parents, children who do not are disadvantaged in relation to most other children in this respect. As a result most other children realise a good that they do not. A moral society should seek to prevent, eliminate or reduce harms to its citizens, especially when they involve the weaker members of the society, since these are the least likely to be able to help themselves. Thus I hold that the rights in the CRC, because they protect the fundamental interests of some of the most vulnerable members of society, are sufficiently important enough to warrant the support of Australian citizens.

In addition, the rights in the CRC protect interests that continue to pertain to the adults that children will become. In other words, the rights enumerated in the CRC are based on interests that all human beings have throughout their lives. Respecting these rights in today’s children is an extension of the interests we adults also have in those same rights. Of special interest in this context, if the rights enumerated in Article 7 were legally upheld for today’s children, this would mean, among other things, that future adults would know the identities of their genetic parents if they chose to (I explain some of the benefits and drawbacks of this knowledge in the following chapter). If we address the right in Article 7 now, it is reasonable
to think that this right would benefit not only today’s children but would continue to benefit their children and so on. If children are misled or denied information about their genetic parents, then their lack of knowledge will be passed on through future generations, depriving their own children and those of their future descendents of the knowledge that Article 7 of the CRC promotes in the best interest of the child.

**Conclusion**

The CRC was intended to provide children with their own set of rights—rights specifically designed for them. This is because children’s interests differ from adults’ interests in important ways. Children were protected by other human rights treaties prior to the CRC, but many of these rights were few or inappropriate for children’s needs. This left the way open for a more appropriate rights treaty to be created specifically for children, resulting in the CRC. The CRC advocates the best interest of the child and it is better able to protect the many fundamental interests of children than other human rights treaties that preceded it. To date the CRC is the most comprehensive and globally accepted treaty regarding children’s rights. Australia ratified the treaty in the late 1990s and committed Australia and its citizens to respecting the rights in it from that time. If we accept that children ought to have legal rights, then the CRC is the most appropriate means to date of addressing children’s interests in the form of rights.

Although the CRC is ambiguous and incomplete in places, a handbook has been developed by UNICEF to facilitate with understanding and interpreting the articles of rights in it. The CRC advocates that children ought to know all their parents, including genetic parents. However, I only argue here for the right to information about genetic parents, which I take to be the content of Article 7.

Under the terms of the CRC, the child is the right-holder. While the CRC is unclear about who the addressee is regarding Article 7, it is my view that there are a number of addressees of this right, which will of necessity need to include the state in the first instance and genetic and social parents in the second and third instances. In the next chapter, I look at what children’s fundamental interests the CRC protects and why it is important that children have information about their genetic parents.
3 Why Information About Genetic Parents Is Beneficial For Children To Have

The rights in the CRC seek to protect important interests and prevent harms. In this chapter, I argue that it is beneficial in several ways to know the identities of one’s genetic parents. First, this knowledge generally makes it easier to find out the medical history of one’s genetic parents and family and by extension one’s own potential future health. Second, this knowledge also generally makes it easier to learn the identities of one’s genetic siblings and half-siblings, if any. The latter knowledge enables one to choose one’s sexual partners in a way that avoids incest and reproductive sexual relations with genetic siblings—something most people want to avoid. Knowing the identity of one’s genetic parents would provide one with increased autonomy—the ability to make better informed choices.

Another benefit of knowing one’s genetic parents that is unlikely to follow from adoption and donor conception is the close match between genetic family for tissue and organ transplant. Organ and tissue transplants are now routine procedures carried out in many hospitals nationally and internationally. Generally, an organ or tissue transplant is more likely to be successful if there is a close match between donated tissue and organ to the donor recipient’s blood group.86 Those children reared within their own genetic family are at an advantage over those who do not know their genetic parents when it comes to organ and tissue transplants from genetically matched donors because they have access to more closely matched potential donors.

When a child lives with and is raised by her genetic parents, she normally knows the identities of those parents. In these cases, a child is very likely to have access to information both about the medical histories of his parents and about the identities of his genetic siblings and half-siblings. The benefits to the child of having this information are likely to follow easily from the household arrangements.

On the other hand, when a child lives with and is raised by adoptive parents or is the product of gamete donation by someone other than the parents who raise her, special measures are needed to ensure that the child is not disadvantaged when it comes to access to goods that others have access to. Thus information about their genetic parents—important information that would follow as a consequence of being reared by their genetic parents—is a good that some children will be deprived of. These households are the particular focus of this

86 Australian Government Organ and Tissue Authority, nd, np.
chapter. Although, I claim that children should have the legal right to information about the identities of their genetic parents, this information only includes their genetic parents’ names. Information about the genetic parents’ nationalities, their susceptibility to genetic health problems and the number and identities of their siblings and half-siblings is additional information that would be beneficial for children to have. However, this additional information should be sought out by children themselves (or social parents on their children’s behalf), should they wish to have it. It is thought that genetic parents should supply this additional information when sought. It is considered that they should provide this information for reasons of beneficence and in order to reduce risks to their offspring. This is information that I will argue is beneficial for children to have in order to be autonomous agents in adulthood and in order to reduce risks to their health and future reproductive choices. This is information that would follow naturally if a child was raised by her genetic parents, as is the case for most Australian children.

While it may be the case that information about the identities of genetic parents is beneficial for children to have, providing it may create a conflict of interests between children and their genetic parents, especially if this information leads to unwanted contact. In this section, I address the potential benefits to children of having this information and some of the risks of not having it. I also address the issue of unwanted contact and ‘abandonment’ issues.

**Explanation**

In this chapter, I discuss contact vetoes. A contact veto is described in the following citation from the Australian Institute of Health and Welfare (2010).

> Any adopted person, birth parent, birth relative, lineal descendant of an adopted person or adoptive parent may register a contact veto. Where a veto has been registered, identifying information is released only after an undertaking not to attempt any form of contact has been signed. An attempt to make contact where a veto is in force is an offence. A contact veto may be lifted at any time by the person who lodged it. 87

I use this understanding of a veto against contact in the following discussion. Taking into account that they can be registered by all those involved in the process, vetoes are enforceable by law and they can be lifted at any time by the person/s who lodged them. It should be noted that vetoes protect the privacy, through contact, of all those involved with adoption and donor conception.

---

**Health Benefits Of Knowing Genetic Parents’ Identities**

As we are all aware, many illnesses and disorders can be attributed to genetic malfunctions. Sometimes these genetic malfunctions are passed on to offspring. We currently know, for instance, that “particular gene sequences have been associated with numerous diseases and disorders, including breast cancer, muscle disease, deafness, and blindness.”88 Cardiovascular disease (CVD)—the term for heart disease, stroke and blood vessel diseases—can be related to genetic family health history.89 According to the Heart Foundation, for instance, “CVD is the leading cause of death in Australia, accounting for 36% of all deaths in 2004. It kills one Australian every ten minutes.”90 Clearly, knowing one has a predisposition for CVD could help reduce one’s risk of suffering a major heart attack or stroke. Many lives could potentially be saved or extended by early diagnoses of this condition. A simple change of diet and exercise regime may be all that is needed in some cases, for example. Someone knowing he has a predisposition to heart disease may be enough to encourage him to take preventative measures to maintain good health. That being the case, it is considered that it is sometimes beneficial for a person’s wellbeing to know the medical history of her ancestors. It is especially so if simple lifestyle changes are all that is required to maintain good health and wellbeing. However, one may only decide to make lifestyle changes when one knows they are required. Information about one’s predisposition to suffer genetic health problems is easier to obtain, of course, when one knows the identities of one’s genetic parents. For this reason, children who have been misled or denied information about their genetic parents, lack information about their genetic health history and, as a result, are at risk of having their welfare choices compromised.

Some adoptees and donor-conceived children, for instance, are denied information about their adoption and donor-conceived status and are, therefore, denied information about their genetic parents’ health history and by extension denied information about their own. Where known, making genetic parents’ health information available to these children would allow them the option of pursuing better lifestyle choices in order to maintain good health. The CRC handbook appeals to the importance of genetic health information as one reason for thinking children should have information about their genetic parents: “For medical reasons alone,” it states, “this knowledge is of increasing importance to the child.”91 Of course, this

---

89 Heart Foundation of Australia, nd, np.
90 Ibid.
statement was made prior to our current ability to detect some genetic disorders through sequencing the human genome. I will discuss human genome sequencing later in this chapter.

**Benefits Of Information In Cases Of Organ And Tissue Transplant**

As doctors increasingly try to prevent us dying earlier than we have to, organ and tissue transplants have increased in number. According to one news article, there have been in excess of 30,000 organ transplants alone in Australia since 1965, not including tissue transplants and skin grafts. Of course, not all ill health is the result of inherited diseases. Some people are ill as the result of an accident. In these cases, it could be argued, that knowing our genetic susceptibility to ill health would not be advantageous here. However, sometimes accidents result in organ and tissue transplants, which require donors. “Organs such as the heart, lungs, liver and pancreas are matched to recipients by blood group, size, compatibility and urgency. Kidneys are matched by blood group.” A close match helps the fight against organ and tissue rejection. A patient’s genetic relatives are the most likely people to be good matches as organ and tissue donors, because they are more likely to match a recipient’s blood group, making rejection less likely. Organ and tissue transplants, whether the result of disease or accidents, are now routine procedures carried out on a regular basis.

However, this is not to suggest that there is an obligation on the part of a donor to provide tissue or organ parts just because they have a genetic relationship to a child. I simply make the argument that genetic family members are more likely to be better matches for organ and tissue transplant than others outside their genetic blood group. In many cases, close relatives are often the first to present themselves as potential donors, knowing a long wait may result in the demise of their relative. This makes it more beneficial to know about one’s genetic family members in cases where there is a need for an organ or tissue transplant than to not know about them. Children living with their genetic parents have the advantage of having their genetic family members available as close blood group matches. Where a child requires a transplant and their genetic parents are unknown to them, the absence of their genetic family members as potential donors is a disadvantage to the child. The rising numbers of tissue and organ transplant operations offer another reason for thinking it important that children have information about the identities of their genetic parents.

---

92 Erdmann, Jeanne, 23/03/2011, np.
93 Ibid.
94 Australian Government Organ and Tissue Authority, nd, np.
While the health considerations raised here are just some of the issues associated with withholding this information from children over their lifetime, there are additional psychological health problems associated with withholding this information until later in a child’s life. I return to these issues in the following chapter.

**Arguments Against The Importance Of Information About Genetic Parent For Health Reasons**

One argument that could be raised against the view that genetic family health information is important is that all kinds of parents are potentially important for a child’s health and wellbeing, that is, there is nothing especially important about genetic parents when it comes to a child’s health and wellbeing. There does not seem to be anything significantly important about genetic family health information, compared to, say, a surrogate mother’s contribution to a child’s health. A non-genetic surrogate mother may affect the health of the child she carries during the nine months of pregnancy and subsequently. For instance, a (non-genetic) surrogate mother may smoke or live in an environment where someone smokes during her pregnancy, which may impact the child’s health during pregnancy and after it is born.

Another argument against the view that providing information about genetic parents is beneficial for health reasons is that certain health conditions, for example, heart conditions, may not yet have affected a child’s genetic family members. If other genetic family members of a child did not suffer any obvious health problems, they may not be aware that they have a potential to suffer any. In such a situation, we may only obtain incomplete health information from genetic parents.

Furthermore, information about many genetic family health conditions is not always passed on to the next of kin. One could imagine, for instance, a situation where someone’s grandparents became deceased early in their lives leaving their children and future grandchildren without information about their genetic health prior to their death.

Another argument against the importance of making information about genetic parents available to children for health reasons, and perhaps the most convincing, is that gene sequencing could allow us to know our predispositions to ill health. Gene sequencing allows people to have their complete genome (the complete genetic material of an organism) broken down into readable sections, which can be used to alert them to any predisposition to genetic
diseases.\textsuperscript{95} Gene sequencing could be used to identify one’s susceptibility to genetic heart problems, for instance. This would allow one to take the same measures that access to genetic family health information would allow.

There are a number of advantages to gene sequencing. This form of identification of genetic susceptibility to ill health may be more reliable than gaining this information from genetic family members. Genetic parents, for instance, may not be aware of any family health problems. Additionally, gene sequencing might be more informative, since this process may be more thorough in its search for genetic health markers. As a result, this method of identifying genetic health conditions may produce more information than genetic parents may be able to provide, because their knowledge may not go back far enough through past generations. If health problems skipped a generation, for instance, some parents may be unaware that there are any genetic health problems associated with their family. So, one possible objection to the above argument that information about genetic parents for genetic health information is valuable is that children do not need to know anything about their genetic family to gain some idea of their vulnerability to ill health; they can avail themselves of gene sequencing, for instance.

Other benefits to gene sequencing include; information about one’s genetic health may be more readily available through gene sequencing for those whose genetic parents are not identifiable; gene sequencing may be more reliable (information gained through gene sequencing is scientifically/technologically obtained whereas people’s memories are notoriously unreliable and this may be true of genetic parents’ memories when it comes to family medical history); gene sequencing may provide more thorough information about one’s susceptibility to suffer genetic health problems than genetic parents can provide.

Thus it could be argued that, following the introduction of gene sequencing, information about genetic parents—for one’s own wellbeing—does not uniquely support providing that information (Of course, I am not relying on one argument alone in support of children’s right to information about their genetic parents and I will come to the others shortly). The value of this benefit can be realised by self-testing alone.

Another argument against the need for information about genetic parents and, indeed, organ and tissue transplant is that there have been advances made in medicine that seek ways for the body to heal itself. One of these advances, for instances, has been the introduction of

\textsuperscript{95} Lo, Dennis et al., 30/04/2010, p. 1. Scientists have recently found a way to isolate the child’s DNA from the mother’s DNA during pregnancy. The cost of obtaining DNA sequencing in vitro, currently $200,660 per child, is prohibitive for the average person.
stem cell therapy. Stem cell therapy is the medical procedure whereby stem cells—the cells in the body that can develop into any type of cell, can be manipulated in the laboratory to become cells in tissue, such as ears, noses and eyes. Most of us have seen on television, for instance, the mouse running around his enclosure in the laboratory with an ear growing out of its back as a result of stem cell manipulation. Stem cell therapy, it is hoped, will replace the need for organ and tissue transplant. Because stem cells have the ability to become whatever cells are needed, they can be used to heal damaged cells. Therefore, it is not difficult to imagine a time when stem cell therapy will regrow new heart tissue or even a new heart, liver, or lungs, for instance. One of the advantages of stem cell therapy is that it would do away with the need for obtaining organ or tissue parts from others.

In addition, since the stem cells would be from one’s own body, the chance of rejection would be reduced or eliminated. Furthermore, there would be no waiting list for tissue and organ patients, something that is currently the case due to the short supply of organ and tissue donors. According to the US National Institute of Health, “Today, donated organs and tissues are often used to replace ailing or destroyed tissue, but the need for transplantable tissues and organs far outweighs the available supply.” The use of stem cell therapy would remove the need for organ and tissue donors and thus waiting times for patients.

There may not be any advantage to knowing one’s genetic parents for organ or tissue donor reasons following greater advances in stem cell therapy. Stem cell therapy may one day eliminate the need of knowing one’s genetic parents and other genetic relatives for health purposes. Thus there are good reasons for thinking that information about genetic parents is unnecessary for children to have in order to assess and maintain their future health potential. However, there are certain problems with each of these arguments.

**The Importance Of Providing Information About Genetic Parents For Health Reasons**

First, I respond to the argument that information is unnecessary because there is nothing particularly special about genetic parents’ health information compared to a surrogate mother’s health information, for instance. I believe there is a distinction between the two. For example, nothing about the non-genetic surrogate mother can impact the child by way of a genetic condition such as Huntington’s disease. This is because:

Huntington’s disease is a neurological condition caused by the inheritance of a defective gene. The death of brain cells in certain areas of the brain results in a

---

progressive loss of cognitive, physical and emotional function. Symptoms tend to first appear when the person is in their thirties or forties.\textsuperscript{97}

A non-genetically related surrogate mother’s family medical history would not provide information about possible genetic health problems such as Huntington’s disease that the child may suffer. This is one distinction between a surrogate parent and a genetic one. For this reason, someone susceptible to genetic health problems may find information about her genetic parents’ health to be beneficial in making informed medical decisions. Indeed, one U.S. surgeon general thought this information an important part of maintaining a state of health: “Being aware of your family health history is an important part of a lifelong wellness plan.”\textsuperscript{98} I take the surgeon general’s reference to ‘family health history’ to mean genetic family health history. The importance of knowing one’s family health history may be because genetic family medical history is used by doctors in order to make informed decisions regarding a patient’s condition. A person whose genetic family displayed a genetic condition could be monitored for signs of that condition. The benefit of this is that early detection can lead to early, more effective treatment, which often offers the best chances of recovery. Therefore, such persons might, depending on the seriousness of their genetic medical condition, be able to avoid future suffering and premature death.

Another genetic illness that it would be helpful to know if one had a predisposition to it, for instance, is Type 2 diabetes (a disease whereby the body fails to produce insulin, which results in the body consuming its own fat and muscle). According to Dr Neville Howard, president of Diabetes Australia NSW, “We need to alert people to realise that family history also means a future risk for children whose parents or grandparents have Type 2 diabetes.”\textsuperscript{99} Again, I interpret Dr Howard’s statement to refer to genetic family health history. While diet and lifestyle are contributing factors to Type 2 diabetes, a predisposition to the disease could be the initial problem. Therefore, knowledge of genetic family medical history could help control or eliminate this illness. Some simple risk reduction measures that are recommended for Type 2 diabetes and that could be utilised if one knew he had a predisposition to the disease are as follows:

1. Watch for signs of the disease (such as increased urine frequency).
2. Get regular screening.
3. Exercise.

\textsuperscript{97} Better Health Channel, 2011(a), np.
\textsuperscript{98} United States Department of Health and Human Services, 2008, np.
\textsuperscript{99} Diabetes Australia—NSW, 2008, np.
4. Observe dietary requirement and weight control. \(^{100}\)

Simple measures like these may also be applicable to other genetic problems. Of course, after developing the disease, preventative measures will be too late. This is one reason why information in advance of developing genetic problems is so important.

Having access to the information about genetic health history is important because people who lack this knowledge may employ inappropriate or unsafe health care measures or take no measures at all to protect themselves. Mary Ladd, a pseudonym, is the mother of two children conceived by donor insemination and she discusses her story in the *Journal of Medical Ethics*. \(^{101}\) One of her children, it was later discovered, was a carrier of hypertrophic cardiomyopathy. \(^{102}\) Ladd received a letter from the donor clinic informing her of the possibility of her children suffering this heart condition following the death of a child who was fathered by the same donor as her children. Ladd had her son checked and he tested positive for the disease. Her son’s cardiologist “stressed that all the affected children would benefit if the individual families and the other doctors involved shared information about the disease.” \(^{103}\) These individual families the cardiologist was referring to were the 14 families that had also obtained sperm from the same donor, amounting to a total of 24 offspring from this single donor, \(^{104}\) all of whom, no doubt, would each also benefit from having information about the donor’s genetic health problems. It should be noted that the information about these donor-offspring children’s potential to suffer hypertrophic cardiomyopathy disease only came as a result of the death of one of the donor’s offspring and not from the donor himself. Had the information come from the donor sooner, that is, when he donated, it may well have helped Ladd’s son and his siblings to receive early treatment for the disease and may well have saved the life of her son’s half-sibling. The potential risks involved in not having genetic family medical information about one’s genetic parents is, in some cases, life threatening.

A parent’s genetic ancestry \(^{105}\) may contain markers for a child’s future health risks. Therefore, having the wrong information or no information at all on one’s susceptibility to suffer genetic medical conditions could result in medical problems and early death.

---

\(^{100}\) Ibid.

\(^{101}\) Ladd, Mary, 2010, p. 479.

\(^{102}\) Ibid.

\(^{103}\) Ibid.

\(^{104}\) Ibid., p. 480.

\(^{105}\) I refrain from using the word “race” here to describe people of African or Hispanic descent, as it is controversial and currently under philosophical debate.
Sickle-cell anaemia is another human genetic disease. Sickle-cell anaemia causes a distortion in the shape of red blood cells, making it no longer possible for blood to flow smoothly through blood vessels, causing problems of clogging.106 “The gene is more common in families that come from Africa, India, the Mediterranean, Saudi Arabia, and South and Central America. In the United States, it most commonly affects blacks and Hispanics.”107 If one was unaware of their genetic heritage and it was Hispanic, for instance, then one could also be unaware of their potential to suffer sickle-cell anaemia. Information about genetic ancestry could be very useful for the health care of children with ancestry that is susceptible to the sickle-cell anaemia faulty gene. Sickle-cell anaemia may present to the family doctor as ordinary anaemia. This could be a problem if the family doctor is unaware of the child’s genetic heritage. Lack of knowledge about one’s ancestry could result in a child suffering more harm than is necessary and possibly dying younger than she otherwise would, from a disease like sickle-cell anaemia, which can be treated simply with folic acid and penicillin.108 However, if a person does not know that she suffers from it, she may fail to take steps to halt or minimise the illness, resulting in the disease progressing and perhaps posing a risk of death. Thus, from a health perspective, the absence of genetic health information could be placing children at risk of early death.

However, it is not only the child herself who may suffer sickle-cell anaemia; her descendents also run the same risk. For this reason it is recommended that

If you carry the sickle cell trait, you may wish to see a genetic counselor before trying to conceive a child. A genetic counselor can help you understand your risk of having a child with sickle cell anemia. He or she can also explain possible treatments, preventive measures and reproductive options.109

Aside from reproductive choices, the correct health information about one’s genetic family may help one to live a longer, healthier life. The absence of that information could adversely affect one’s wellbeing. Consequently, people who have the correct information about their genetic families are better placed to make informed medical decisions than those who do not have this information or have the wrong information, because the former have important knowledge about themselves that the others lack. And, if there are genetic health problems in a family, then reproductive choices may be impacted.

106 Mayo Clinic, 2011, np.
107 Ibid.
108 Ibid.
109 Ibid.
Furthermore, there are benefits of knowing one has a family history of genetic bowel, breast or skin cancers, for instance, because there are free screening tests provided in these cases. According to the Victorian Department of Health,

Screening tests aim to find disease in the early stages before it causes symptoms. Genetic screening tests are available for people with an established family history of bowel, breast or skin cancers. In most cases, early detection of cancer increases the chances of successful treatment. Screening for disease has helped reduce the number of fatalities. Cancer screening has dramatically reduced illness and death rates in Australia. For example, since the Cervical Screening Program was introduced in the 1980s, the death rate from cervical cancer in Victoria has gradually declined and is now among the lowest in the world.\textsuperscript{110}

The importance of early screening tests for genetically related health conditions is noted by Professor Ian Hamilton-Craig, Professor of Preventive Cardiology at Griffith Health Institute. Hamilton-Craig is working to increase Australian awareness of genetic high cholesterol—otherwise known as familial hypercholesterolemia—and is working to reduce premature heart disease. Hamilton-Craig is calling for “A national Medicare-funded screening program for genetic high cholesterol”\textsuperscript{111} which he argues “is urgently required to provide a powerful weapon in the fight against heart disease.”\textsuperscript{112} Hamilton-Craig estimates that “around one in 300 people are born with the gene mutation. It explains the high cholesterol levels in people who die at 45-55 years of age due to coronary disease who were previously symptom-free.”\textsuperscript{113} Because screening is not free for this genetic condition Hamilton-Craig continues, “Additionally, there is currently no Federal reimbursement for FH DNA screening and private testing comes at considerable cost to patients.”\textsuperscript{114} The availability of free screening for high cholesterol will most likely change in the future and like screening for bowel, breast and skin cancers will be only available to those with a genetic family history of the disease. Clearly, therefore, knowing one is susceptible to a genetic disease such as bowel, breast and skin cancers is beneficial for better health treatment and in some cases can entitle one to free screening to detect one’s susceptibility to future genetic health conditions. Children who are raised within their genetic family most generally are aware of their family health history. However, children who are not raised by their genetic parents may not be able to take advantage of these free screen tests for genetic disease even if they are potentially at risk of

\textsuperscript{110} Victoria Department Of Health, 2012, np.
\textsuperscript{111} Griffith University, 2012, np.
\textsuperscript{112} Ibid.
\textsuperscript{113} Ibid.
\textsuperscript{114} Ibid.
suffering one of them. Therefore, some of these children will lack a good to which others have free access. Thus these children will be disadvantaged when it comes to healthcare.

In response to the argument that we can only obtain incomplete information from some genetic parents, it is very possible that if health information is requested from someone, certain health conditions, for instance, heart conditions, may not yet have presented themselves. So, there may well be instances where people do not have genetic health information to pass on to their children. There is no denying that where information is unavailable it is difficult to provide it. I accept this argument. However, where information is available that could alert a person to the possible risks of ill health, should we not make it available to that person in order that they may take steps to reduce their risk or potential risk or, at the least, offer them the choice to do so where we can? It seems to me that this option would be more in keeping with Article 7 of the CRC and a morality that seeks to reduce potential risks to children where possible.

In response to the argument that gene sequencing will prove it unnecessary to obtain genetic parents’ health information, there are problems with this view also. For instance, while gene sequencing seems to offer a number of benefits, there are a number of problems related to gene sequencing that prevents many people availing themselves of its benefits. For instance, gene sequencing is very expensive. According to Jennifer Turcotte from Complete Genomics; “Pricing starts at $20,000/sample for very small projects of 8 genomes or more. We do not accept projects of less than 8 genomes. We have volume based pricing starting at 16 samples or more where the price per sample is $12,500.”115 Of course, while it is recognised that gene sequencing is very expensive, this may change. Indeed, according to an article in The Wall Street Journal by Jacob Goldstein, to encourage the race for cheaper genome sequencing, philanthropist Steward Blusson is offering a US$10 million prize to the first company that can sequence 100 human genomes in ten days for $10,000 or less per genome.116 Blusson’s offer is a good incentive to promote a cheaper and faster method of sequencing the human genome in an effort to make it more cost-effective for the public.

However, even if the cost of gene sequencing were reduced to $1,000 per genome, perhaps a long way off given that the race is on to bring the cost of a single genome down to $10,000, that price would still be prohibitively high for some people. Furthermore, having the means to obtain health information in this way could cause further social injustice for those

---

115 Turcotte, Jennifer, (14/07/2010), np.
116 Goldstein, Jacob, 2007, np.
families who cannot afford to pay for this service, by providing only those with the means to pay with the opportunity to make informed choices. This may have the effect of marginalising adoptees and donor-conceived children.

Furthermore, it is not only costs that are problematic when it comes to gaining health information from gene sequencing. In a recent newspaper article, Dr Christine Patch, a genetic counsellor and chairwoman of the British Society for Human Genetics, stated “It is too early to apply the technology widely as we are not yet able to interpret many of the results that can be generated accurately.”\textsuperscript{117} Furthermore, we still do not understand the “exact gene number, exact locations, and functions of genes.”\textsuperscript{118} In a Drug Discovery & Development online article (published 30th April 2010), Muin Khoury, director of the National Office of Public Health Genomics at the US Centers for Disease Control and Prevention, said, “We simply cannot interpret the vast amount of emerging data. The current information is incomplete, uncertain, potentially misleading and could lead to unnecessary procedures.”\textsuperscript{119}

In addition, Francis Collins, director of the US National Institutes of Health, who led the team that first sequenced the human genome, said in a 2010 Sunday Times article, “far too many doctors in Britain and America lacked the training they will need to use DNA-based medicine.”\textsuperscript{120} He adds, “Few doctors understood enough about the way genetics contributed to drug responses and common diseases to exploit such advances.”\textsuperscript{121} Collins also said that some doctors “claimed genetics was unimportant to their clinical practice, despite its contribution to disorders such as heart disease, diabetes and Alzheimer’s.”\textsuperscript{122} At present there are very few doctors qualified to interpret or make use of genetic sequencing. Therefore, gene sequencing is currently of little value to the general public and their physicians. Furthermore, availing ourselves of poorly understood health information could prove to be dangerous.

Granted, one day gene sequencing will be able to identify health problems that are a result of our genetic makeup at a reasonable cost and it will be unnecessary to know what medical problems our ancestors had. However, this is still a long way off. This has led Joann Boughman, CEO of the American Society of Human Genetics to suggest that “One’s own family history of heart disease—the number of parents and grandparents who died from heart attacks—gives as much information as a person needs to make lifestyle decisions that affect

\textsuperscript{117} Alleyne, Richard, 09/12/2010, np.
\textsuperscript{118} Ibid.
\textsuperscript{119} Cheng, Maria, 30/04/2010, np.
\textsuperscript{120} Henderson, Mark, 24/02/2010, np.
\textsuperscript{121} Ibid.
\textsuperscript{122} Ibid.
heart health.” Presumably this could also apply to other genetically related medical conditions.

In response to the argument that stem cell therapy would remove the need for genetic family health information in cases of tissue and organ transplants, one noted problem with this argument is that stem cell therapy is still in its early stages and growing hearts and lungs is still a long way off being available to those who currently need this treatment. According to the US National Institute of Health,

> Given their unique regenerative abilities, stem cells offer new potentials for treating diseases such as diabetes and heart disease. However, much work remains to be done in the laboratory and the clinic to understand how to use these cells for cell-based therapies to treat disease.\(^{124}\)

As in the case of gene sequencing, stem cell therapy may provide advantages to future children. However, today’s children are currently unable to be helped by gene sequencing or stem cell therapy to the extent that information about genetic parents’ health is unnecessary. Thus, there is still the need for the large number of organ and tissue transplants currently taking place.

Due to the problems associated with all the above arguments against the need for information about genetic parents for health reasons, knowledge of one’s health susceptibility gained from genetic family members is still the easiest, most useful, and least costly way to be informed of potential genetic health problems. Therefore, it seems reasonable to argue that children would benefit from access to this information.

Genetic family health information is information that is beneficial for children to have and would be naturally available to them if they lived with their genetic parents. The easiest way to get information about our susceptibility to genetic health conditions is to ask one’s genetic parents. Of course, this is only possible if one knows who one’s genetic parents are. Those denied information about or misled about their genetic parents are at a disadvantage in relation to an important welfare good, one to which those who are cared for by their genetic parents would have natural access. However, it is not only for health reasons that this information is important for children to have.

\(^{123}\) Erdmann, Jeanne, 23/03/2011, np.

\(^{124}\) National Institute of Health (US), 2009, p. 2.
The Potential Risk Of Incest Occurring

Another potential risk to children who are never told they are adopted or the result of gamete donation, for instance, is the possibility of incestuous relationships forming between not only genetic parents and their offspring, but also between sibling and half-siblings. The possibility of unknowingly forming incestuous relationships as a result of not knowing about one’s siblings and half-siblings is another reason why it is beneficial to know about one’s genetic parents. Information about their identities would allow people to better avoid unknowingly having sexual relations with their genetic parents or their siblings. There is a possibility, even if a small one, that those who are never informed about who they are closely related to genetically will unknowingly commit incest. Parents and siblings are the closest genetic relatives we recognise. The identities of parents and the number, identities and ages of siblings and half-siblings would be important information, therefore, for children to have in order to avoid forming sexual relationships with their closest genetic relatives. Consanguine relationships may form in the absence of this information, not only between uninformed brothers and sisters, but also between uninformed genetic parents and their offspring, as it is not unusual for younger persons to form sexual relationships with older individuals.\textsuperscript{125} Therefore, another reason that children ought to have a legal right to information about their genetic parents is to gain information about them and about their siblings and half-siblings so as to avoid the risk of forming incestuous relationships with them.

The CRC promotes a child’s right to preserve her family relationships. According to Article 8(1), State Parties undertake to respect the right of the child to preserve his or her identity, including nationality, name and family relations as recognized by law without unlawful interference.\textsuperscript{126} Note that Article 8 requires states to ‘respect the right of the child to preserve’ those family relationships that are ‘recognised by law’. The expression ‘recognised by law’ can apply to family relationships other than genetic relationships, such as adoptive family relationships. However, it could arguably include genetic family relationships.

Genetic family relationships are especially important in law. The law recognises and bans close genetic relatives from marrying each other. Therefore, even if one is adopted and the adoptive family is recognised in law, the law still recognises the closeness of genetic parent

\textsuperscript{125} The myth of Oedipus may yet become a reality. Oedipus, who did not know he was adopted, killed his genetic father and married his genetic mother without knowing they were related to him.

\textsuperscript{126} Office of the High Commissioner for Human Rights, 2007, np.
and sibling relationships and forbids them legally marrying one another. According to the Australian Marriage Act 1961, it is forbidden for marriage in Australia to occur:

(a) “between a person and an ancestor or descendant of the person”; or

(b) “between a brother and a sister (whether of the whole blood or the half-blood).”

This is more easily avoided when you know who to avoid having consanguine relationships with. Withholding information about genetic parents and siblings and half-siblings could, therefore, impact decision making when considering future relationships.

Children should not only have information about the identities of their genetic parents and siblings and half-siblings, but they should also have information about the ages of those siblings. This is because siblings and half-siblings born as a result of IVF will roughly be the same age and, if born in the same neighbourhood, may frequent the same areas. They could associate with the same people, risking the formation of intimate relationships among them.

The lack of sufficient government regulations and guidelines on the gamete donation industry allows for this possibility. According to the Australian Senate Committee in its report on donor conception, “A number of submissions [to the Senate Committee] noted that the inconsistent approaches between the states and territories regarding registration of donors mean that there is no way of accurately knowing or controlling the number of families a particular donor assists.” As a result, the report stated the need for the Australian government to introduce guidelines on the appropriate number of families who can receive gamete donations from a single donor.

However, even with these new regulations in place, it is possible that the guidelines would be ignored, after all these are commercial enterprises and donors could go from clinic to clinic making donations. According to Neroli Sawyer of the University of Ballarat, who has researched Australia’s IVF regulations, record keeping and guidelines for gamete donations in Australia are not being kept or followed. She argues that “It is important to have an accurate model for calculating limits to sperm donation so as to avoid inadvertent half-siblings mating.” However, even if the clinics enforced strict regulations on donor numbers between clinics, people need not go to clinics to avail themselves of this service. For instance, one could possibly buy sperm over the internet or obtain it from a friend or relative. Who could keep count of the number of children born in that case? All this suggests that no

---

127 Attorney-General's; Families, Housing, Community Services and Indigenous Affairs, 2011, (23(2)).
128 Parliament Of Australia (Senate), 2011, np..
129 Ibid.
131 Ibid.
one can really keep count of the numbers of related children being born as a result of gamete
donation from a single donor in the same jurisdiction, or, if they can, then it may not be
possible to enforce limits on the number of donors who provide gametes outside of regulated
clinics.

Of course, this is not just a problem for donor-conceived children; according to a 2008
newspaper article by Fiona Barton, adopted children are also at risk of forming consanguine
relationships with their siblings when they are separated at birth or in early childhood.132
Indeed, there is already evidence of this occurring. In Ireland, according to a news report by
Valerie Hanley for the *Daily Mail*, a half-brother and sister, James and Maura (pseudonyms
used in interviews to avoid stigmatisation of their son), married and had a child before
finding out that they were blood relatives.133 They blame the judge who made the decision to
withhold the identity of James’ genetic father after the father tried to gain custody of James as
a child.134 Clearly, there are risks of incest occurring when one withholds information about
genetic parents and siblings. The most notable problems with incest are: it is illegal; there is a
taboo attached to it; there are health risks for any offspring that result; and there is risk of
stigmatisation being attached to those children—the reason used for the pseudonyms in the
Irish case.

The possibility of the same type of relationship forming between donor-conceived
children was raised by Liberal Democrat MP Lord Alton in the British House of Lords on the
*Human Fertilisation and Embryology Bill* debate.135 Lord Alton’s concern ought not to be
dismissed out of hand simply because it relates to Britain, as there were 7,913 Assisted
Reproduction Technology (ART) births in Australia and New Zealand in 2004. A little less
than half (46.5%) of those were by donor conception, and the majority were in Australia.136
According to Yueping Wang et al., of the Australian Institute of Health and Welfare (2010),
there was “a steady increase in the number of clinical pregnancies and live deliveries
resulting from ART [assisted reproductive] treatment between 2004 and 2008.”137 If the
numbers of donor-conceived children are increasing, then the rising numbers of children born
as a result of gamete donation increases their chances of consanguine relationships forming

---

132 Barton, Fiona, 13/01/2008, p. 33. In another case in England, twins recently married without realising they
were genetically related. The twins were separated at birth and as a result neither of the twins knew they were
related to one another.

133 Hanley, Valerie, 30/05/2010, np.

134 Ibid.

135 Barton, Fiona, 13/01/2008, p. 33.

136 Wang, Yueping Alex et al., 2006, p. xiii.

137 Wang, Yueping Alex et al., 2010, p. 43.
between them. Therefore, aside from information about genetic health conditions, it seems reasonable to think that it would also be beneficial for children to be informed about their genetic parents, siblings and half-siblings, where any exist and this information is known. Therefore, aside from the names of parents, it would also be beneficial to know something about the identities, number, gender and ages of siblings and half-siblings in order to identify close family members. Lack of this knowledge could lead to incest, a practice that is not only taboo, but is also illegal in Australia. Even if the risk of incest occurring between donor-conceived children and their genetic parents and siblings and half-siblings is low, it still seems an unacceptable risk, given the risk could be avoided by providing people with information about their close genetic relationships. The risk to donor-conceived children is heightened by the fact that consanguine relationships has already occurred between adoptees and the numbers of donor-conceptions are increasing, meaning more donor-conceived children are at risk.

One proposal to combat the problem of donor-conceived children forming consanguine relationships is to curtail the number of gamete donors. However, the validity of curtailing the number of donors in order to address the issue of consanguinity is challenged by Louise Jamieson and the International Donor Offspring Alliance, who defend the alternative of identifying donors instead.\(^{138}\) However, even if we curtail the number of donors and donations, it is still important that children should have information about the identities of their genetic parents and siblings and half-siblings in order to avoid even the slightest chance of unintended incest occurring.

Information about genetic parents is not only beneficial for health reasons, therefore, but it is also beneficial for preventing unintended incest occurring. Information about siblings and half-siblings does not require contact with genetic parents or siblings. It merely requires that the information be made available by genetic parents to their children. This information could be passed on to the child via an agency, for instance, if she requested it.

**Problems With This View**

Of course, not everyone is of the view that incest is morally wrong. It could be argued, for instance, that just because incest is illegal and taboo in Australia and most westernised countries, this may have more to do with social norms than a universal moral code. For instance, incest is an acceptable norm in some societies. The Egyptians were the most well

\(^{138}\) Parliament of Australia (Senate), 2011, np.
known of the societies who accepted incest as part of a royal marriage. Most people know, for instance, that Cleopatra married two of her brothers. Of course, she was not the only Egyptian Pharaoh to do so. According to one writer on Egyptology,

The right to the throne came with the daughter of the king and his queen. She was the royal heiress, although not for herself but for her husband, and marriage to the heiress was apparently necessary to legitimise a ruler’s kingship. A prospective king therefore sought to marry the heiress, who might be his sister, half-sister or other close female relative.\textsuperscript{139}

It certainly appears as though sibling relationships were an acceptable norm for some royal families in the past, which may suggest that our views on the wrongness of incest are a modern notion rather than a universal moral norm.

Furthermore, while incest is taboo today, this may be more to do with social norms, since it was once taboo to admit one was homosexual or bisexual; something that is generally accepted today. In many conventional societies, it is quite permissible for people to express their sexual preferences without causing too much concern. My point is that norms change over time and it is possible that our current norms on incest may change at some time in the future. Since it is not a universally held moral consideration, the taboo against incest could just be another convention—something that possibly resulted from religious dogma. As a result, there may be nothing intrinsically wrong with incest between two consenting adults.

\textit{Response To The Arguments Regarding Incest}

It may well be true that the taboo against incest is a social construct, and, therefore, not a moral norm. However, it is generally accepted that there are a number of problems with incest that impact on the morality of the issue. For instance, most are aware of the problems associated with reproducing offspring with closely linked genetic relatives. It is generally understood that a person who procreates with a close genetic relative, where there is a genetic health condition, have a greater chance of bearing children who will suffer from that genetic condition. While the risks are increased for children born of an incestuous relationship, of course, not all children will suffer a genetic medical problem as a result of their parents being closely related. However, there is a greater risk to the health of offspring where there are very close genetic ties between their genetic parents. Aside from this risk to a future offspring’s potential health, the moral judgment against incest, some may think, is unwarranted.

\textsuperscript{139} Estensen, Mirian, 1998, p. 87.
However, to deliberately choose a genetic sibling to marry is a choice that should not be taken lightly, unless it has been decided to forego having children from the union. However, if siblings choose to have children together, then they should be alerted to the possible health consequences for their future children. People knowingly entering into an incestuous relationship do so with full autonomy when they are informed of the possible consequences of their actions. Unfortunately, when people unknowingly enter into an incestuous relationship, their choice to do so and to reproduce children is made without the full knowledge of all the facts of their genetic connectedness available to them. This reduces their autonomy in making future partner choices and reproductive choices. I return to the issue of autonomy shortly.

However, it is not just that incest is taboo; it is also illegal in Australia. People breaking the laws by marrying their sibling, for instance, could possibly face penalties or have their personal lives exposed to the general public. The exposure of incest could see people having to face problems of stigmatisation. However, the stigmatisation attached to the taboo of incest would not only affect the persons involved, but also their children. Parents may be willing to accept this risk for themselves when they know what they are doing and they have a choice in the matter. However, to expose their children to this risk seems to me unfair on the children. Therefore, the risks and taboos associated with incest pose a threat to children even where their parent siblings choose this as an option.

The Arguments Regarding The Availability Of Information About Siblings

Another argument against the benefits of genetic parents providing information to their children about their siblings is that information provided at the birth of a child will not give a complete picture of the child’s siblings and half-siblings. It will not, for instance, be able to identify future siblings of a child. This may be true. However, this is true for all people. As each child is born into a family she only has information about the children that preceded her. Nobody can know in advance the identities of those siblings that have yet to be born. In this respect, adoptees and donor-conceived children are no worse off than others. However, children who are raised by their genetic parents will know each child that preceded them and they will know each new sibling as they are born. The problem for adoptees and donor-conceived children, for instance, is that they do not have this same advantage of knowing who their siblings are or will be, unless this information is made available to them as each child is born. Therefore, it is important that children are provided with information about the
number and ages of each of their siblings and half-siblings as they are born in order to avoid unintended incest with them.

**Increased Autonomy From Having Information About Genetic Parents**

In addition to being beneficial for health reasons and incest avoidance, information about genetic parents is also beneficial for autonomy reasons. There is much debate in philosophical circles regarding autonomy and what autonomy means. For instance, according to the philosopher Gerald Dworkin, in *The Theory and Practice of Autonomy*, autonomy is used sometimes as an equivalent for liberty..., sometimes as equivalent to self-rule or sovereignty, sometimes as identical with freedom of the will. It is equated with dignity, integrity, individuality, independence, responsibility, and self-knowledge. It is identified with qualities of self-assertion, with critical reflection, with freedom from obligation, with absence of external causation, with knowledge of one's own interests. It is related to actions, to beliefs, to reasons for acting, to rules, to the will of other persons, to thoughts and to principles.\(^{140}\)

Clearly, the subject of autonomy conveys a number of ideas covering a diverse range of topics. The philosopher Marina Oshana, in *How Much Should We Value Autonomy?*, suggests two ways of viewing autonomy, either as a ‘global’ or ‘local’ phenomenon. She states,

> Personal autonomy as I construe it is a ‘global’ phenomenon, a property of a person’s life that expresses and unifies the will and choices of the person. By contrast, the ‘local’ or occurrent sense of autonomy is a property of a person’s acts or desires considered individually, and pertains to the manner in which a person acts in particular situations. In the global sense, a self-directed individual is one who sets goals for her life, goals that she has selected from a range of options and that she can hope to achieve as the result of her own action. Such goals are formulated according to values, desires, and convictions that have developed in an uncoerced fashion. They are goals that the individual would affirm as important to her were she to reflect upon their origin and content.\(^{141}\)

Dignity, integrity and self-knowledge, for instance, inform a great deal of discussion in moral philosophy. As I do not wish to expand my discussion to cover too broad a range of subjects in my endeavour to focus in on a child’s right to information about their genetic parents, I curtail my discussion to a simpler idea of autonomy for the purposes of this thesis. However, this is not intended to lose sight of the ways in which autonomy is equated with such valuable goods as dignity, integrity and self-knowledge, but rather to simplify matters, in order that we might focus more on the problems resulting from reduced autonomy. From Dworkin’s statement we get the idea that autonomy has something to do with self-rule and self-assertion.

---

\(^{140}\) Dworkin, Gerald, 1988, p. 6.

\(^{141}\) Oshana, Marina, 2003, p. 100.
From Oshana’s statement we get the idea that autonomy is, in the global sense, the ability to take control of one’s life, to self-govern, to set goals selected from a range of options, without being coerced in any way. It includes the idea of making decisions without being controlled or manipulated by others. It is on these understandings of autonomy that I argue that children are impacted through lack of information about their genetic parents.

As it is equated with such things as the aforementioned ideas presented by Dworkin and Oshana, it seems reasonable to argue that autonomy is something that people value and that children, when they achieve decisional capacity, would be no different in this respect to others. Of course, it is accepted that there will be some who would surrender their autonomy willingly, such as the self-imposed slave, that is, the person who chooses to surrender his autonomy in order to lead the life his master chooses for him. However, it is thought that such a person has only been able to choose this path in life when he is autonomous to begin with. From an autonomous position one can choose to be a slave, but from the position of a slave one cannot choose to be autonomous, unless that autonomy is granted by the slave’s master. Thus the unwelcomed positioned, by most of us, is that of the slave. Aside from those sorts of cases, it is generally thought that people prefer autonomy over slavery, where a person is not free to control his life, to self-govern, to set goals from a range of options, where he is coerced and manipulated. Indeed, if Dworkin is correct, “About the only feature held constant from one author to another are that autonomy is a feature of persons and that it is a desirable quality to have.”

Thus it is considered here that autonomy is a valued good that people want to have. It is thought that this also includes children when they gain the ability to be autonomous agents.

Given that autonomy is a valued good that people want to have, a persons who lacks autonomy or whose autonomy is reduced through manipulation or coercion is lacking a valuable good. In the cases of children, their future selves will lack this valuable good. Children are not autonomous agents, but will be one day. As noted in Dworkin’s statement at the beginning of this section, one of the ideas equated with autonomy is ‘critical reflection’. It is thought that to be autonomous an agent needs to be able to critically reflect on his choices. This is clearly not something that is expected of very young children, neither are the notions of responsibility and independence. If we tie these concepts to the concept of autonomy, then children cannot count as autonomous agents. Nonetheless, when considering children, we should also consider their lack of autonomy as a temporary state of affairs from which they

142 Dworkin, Gerald, 1988, p. 6.
will at some point in time emerge when they will be considered independent and responsible. As Oshana rightly observes, “Ideally, of course, children will acquire the necessary characteristics for self-determination as they mature.” I think there are very few who would disagree with this observation. As it is expected that children will one day acquire self-determination, independence and responsibility, this is, in my view, reason enough to include them among those persons whose future autonomy should be considered a valuable good.

Given the importance of autonomy to people, a person who lacks autonomy or whose autonomy is reduced through manipulation and coercion is lacking a valued good. This is because a person who lacks information about her genetic health, for instance, is unable to act in a fully autonomous way in regards to their health and wellbeing. Where health information is deliberately withheld from a person, for instance, it could be argued that she is being manipulated and coerced. Whether it is for her own good or not does not detract from the fact that her autonomy is compromised. If autonomy amounts to self-control over one’s life and choices, then information about one’s susceptibility to ill health would be beneficial in making medical decisions and other important decisions such as whether to have children or not.

Children who are never told the truth about their genealogy may have reduced autonomy in later life compared to other persons in regard to the choices they will make, such as their reproductive choices. Parents may unknowingly reproduce children who will suffer terribly from a genetic condition: such parents would otherwise refrain from reproducing if only they knew the risks. Or they may decide not to produce children because they believe, wrongly, that they will produce a child who will suffer. Many of our choices might have been otherwise if we had had certain facts in advance.

While it is recognised that children are not fully autonomous agents, it is nonetheless assumed that they will become autonomous adults in time. Indeed, many children’s rights not only relate to their present wellbeing but also their future interests. Article 7 could be viewed in this way. Therefore, if we fail to inform a child about her genetic heritage when this information is available, we may lessen the child’s autonomy in adulthood, even if we do not intend to do so. Lacking information about the identities of her genetic parents makes it more difficult for the future adult the child will become to make informed decisions regarding issues such as health, marriage, and procreation.

143 Oshana, Marina, 2003, p. 103.
Of course, some social parents who do not provide information about their adopted child’s genetic parents may not necessarily be manipulating their children. Some social parents simply may not have any information to pass on to their children, despite a desire to do so. For instance, social parents of ‘abandoned’ children rarely have such information available to them about their child’s genetic parents. Other parents may not provide the information to their children because they may not want to disrupt their current family relationships.

However, it is generally recognised that to make good choices, we need all the relevant facts we can gather. Imagine two people trying to decide which of a number of options to choose from. One person has all the relevant facts of the matter at hand, while the other person has no facts whatsoever to rely on, or, worse still, has the wrong information. The person with no facts or the wrong information cannot make an informed decision, because, quite simply, he is not informed. He could, perhaps, make the same choice as the person with all the facts, but it would not be an informed choice. The best this person could do is guess. While it is true that the person without any facts may make the correct decision regardless, we should think their decision not as well justified as that of the informed person, who deliberates on the matter and makes her decision based on knowledge and reason. The ‘factless’ person’s decision, despite it having the same outcome as the person with the facts, is uninformed. Autonomy, the ability to self-govern, is impacted when information that could help us make informed decisions is withheld from us, when we are coerced and manipulated into believing something false about ourselves—impacting our self-knowledge (I return to the issue of self-knowledge in chapter 6 with discussion of David Velleman’s views on non-disclosure to donor-conceived children). The lack of information about genetic parents impacts our self-knowledge and could impact our decision making choices, thereby impacting our autonomy.

**Impact On Genetic Parents**

There are a number of benefits to children having certain information about their genetic parents and risks to them not having it. So, there are good reasons why children ought to have a legal right to information about their genetic parents. However, one reason for thinking that children should not be provided with this information about their genetic parents is that it would identify their genetic parents, allowing children to make contact with them. For instance, some children may want to meet their genetic parents in order to form relationships with them. This could be problematic if genetic parents did not want to be contacted or they
had a right not to be contacted, such as through a contact veto. Where this occurs, it should be remembered that numerous parents gave up those children for adoption or donated gametes under the conditions of anonymity. This being so, allowing identifying information to be given to their genetic offspring could be considered an infringement of the genetic parent’s right not to be contacted.

Furthermore, even where a child does not wish to make contact with her genetic parents, there may still be a conflict of interest between a child’s right to information about her genetic parents and her parents’ right to withhold it (should such a right exist). For instance, her genetic parents may not wish to provide this information. They may consider their obligations to the child to have ceased when they placed her for adoption or donated the gametes that created her. It is easy to imagine cases where parents who placed their children for adoption or donated gametes under the veil of secrecy or anonymity expected never to hear from their children again. The genetic parents’ right to privacy and to withhold information from their genetic children is a forceful reason why children should not be provided with information about them.

Other Objections That Are Raised In The Following Chapters

Another objection to children being provided with information about their genetic parents is that the child may not want this information (I discuss children’s interest in having this information in the next chapter). Further cases where it may not be in the child’s best interest to know the identities of her genetic parents includes situations where there is danger to the mother or child—the child’s father is a paedophile, rapist or murderer. I discuss these cases in a later chapter. Leaving these cases aside for the moment, I will now concentrate on arguments in support of making information about genetic parents available to children.

In Defence of Providing Information

While it is understandable that some children may want to meet their genetic parents, as previously stated, I do not argue for contact between genetic parents and their children; rather, I simply contend that it is beneficial for a number of reasons for children to be provided with certain information about their genetic parents and risky for them to be without it. Furthermore, it should be noted that not all children will want to meet their genetic parents; some will be content to receive the information they need without contact.

However, in those cases where children seek contact, it is possible for those parents who do not wish to be contacted by their children to prevent this from occurring. Adoptee and
donor registers that allow information to be passed between children and their genetic parents and vice versa can include no-contact vetoes, preventing either party from contacting the other without the consent of both.\textsuperscript{144} This system is currently in place in New South Wales,\textsuperscript{145} for instance, for both adoptees and donor-conceived children and, although it does not satisfy the needs of those children seeking to make contact with their genetic parents, it still allows for information to be passed on from those parents to their children. This, by itself, is ultimately what is beneficial for children.

In addition, we ought to respect genetic parents’ wishes not to be contacted where vetoes have been put in place. However, even in states where there are no provisions for vetoes, but where genetic parents make it known they do not want contact, we ought to respect those genetic parents’ wishes as this option may be what is ultimately in the best interest of the child, especially if their genetic parents are abusive, for instance. The guarantee of anonymity and the desire not to be contacted could be strong reasons for thinking that we ought to respect genetic parents’ rights not to be contacted.

However, even if genetic parents have strong reasons to deny contact, it is arguable that they have a right to withhold information. Even if it could be said that genetic parents have a right to withhold information about themselves, if there is no strong reason for doing so, then they should provide it, in the best interest of their children. Given that we should ascribe primary concern to the child’s rights as advocated by the CRC (refer to chapter 2), then as children need to have this information, their needs should be considered weightier than their genetic parents desire to withhold it. Clearly, for the aforementioned reasons, it is important for a child to have access to information about his genetic parent’s family medical history and the identities of his siblings and half-siblings. We would not want to see children disadvantaged through lack of this information, which in many ways could be essential to their well-being and future autonomy. Providing, of course, that a parent’s right (should there be one) to withhold this information is not as morally weighty as a child’s right to access it, if they so choose, we ought to support the child’s right. Where there are no good reasons for genetic parents to withhold this information from their children, they should provide it on grounds of beneficence and in order to reduce harms.

The arguments presented here regarding the benefits to children of having information about their genetic parents, sibling and half-siblings and the possible risks associated with

\textsuperscript{144} Wang, Yueping Alex et al., 2006, sect 154.
\textsuperscript{145} New South Wales Law Reform Commission, 2002(b), 4.8.
them not having this information are, in my view, sufficiently important enough reasons to warrant rights protection and in particular the right contained in Article 7 of the CRC. It is problems such as the ones included in this chapter that the right in Article 7 of the CRC seeks to address. By incorporating Article 7 into law, we may prevent such problems from occurring. For this reason Article 7 of the CRC is a benefit for children.

**Conclusion**

If children are never informed that they are adoptees and donor-conceived children, then there is a risk of them not being informed of their genetic family health history. This could lead to them being unaware that they could suffer from genetic health problems. Adoptees and donor-conceived persons who are never informed of their adoptee and donor-conceived status are also at risk of forming consanguine relationships with their genetic parents, siblings and half-siblings. Children who are never informed may also have reduced autonomy in their adult years. Although we can determine if a person is susceptible to a genetic health condition through gene sequencing, scientific advances that allow health to be fully determined this way are as yet unusable by the medical profession or the general public. And, although this may change, the costs incurred in determining health this way are prohibitive for most people and the results unreliable. While stem-cell therapy offers hope of healing ourselves, this advancement is not yet at the stage where it can heal us; we are still reliant on organ and tissue donors.

The easiest and most inexpensive way to find out what a child’s predispositions to genetic illnesses are is to find out what health problems have developed in her genetic family. Health information gained from one’s genetic family is more readily available, more cost effective and more reliable than the other methods discussed, leading to better health and greater autonomy for individuals when making informed health choices.

While incest may have been accepted in some societies in the past, consanguine relationships between children and their genetic parents or siblings are not generally accepted today. They are certainly not accepted or permitted in Australia. While reasons for this may not be clear-cut and obvious, it is generally accepted that one reason for avoiding this sort of relationship is because it is beneficial for the well-being of offspring, who may be more prone to genetically inherited diseases where both parents have the same predisposition to genetic problems. In addition to medical problems, incest can lead to stigmatisation for children born as a result of this type of relationship. Therefore, in order to avoid unknowingly forming consanguine relationship with one’s family members, it would be beneficial to children to
have an account of the identities of their genetic parents and the number and ages of their siblings and half-siblings. Without factual information about their genetic health risks and the members of their genetic family, children run the risk of having reduced autonomy in adulthood. It is these problems that the right in Article 7 of the CRC seeks to address and prevent before they become problems. Article 7 of the CRC is a benefit for children, which is why, I will argue in the next chapter, children want to know the identities of their genetic parents.

The arguments raised in this chapter highlight the problems that children may face if they are never informed that they are adopted or donor-conceived. However, there are other arguments that highlight the problems children may face if they are only informed of their adoptee and donor-conceived status later in life. In the next chapter, I address the strong desire some adoptees and donor-offspring have to acquire information about their genetic families and the possible psychological problems they may experience if this information is withheld from them until later in life.
4  Children Want To Know

In the previous chapter, I argued that there are health, reproductive and autonomy reasons for why children should have information about their genetic parents. Adoptees and donor-conceived children are especially at risk of being deprived of this information. In this chapter, I add another argument for the importance of children having this information. Adopted and donor-conceived children often express a strong desire to know the identities of the genetic parent/s with whom they are not acquainted. They sometimes express this as a search for self in order to provide a complete account of their narrative identity. In addition, adoptive and donor-conceived children may suffer psychological consequences if deprived of information about their missing genetic parents until later in life.

In this chapter, I provide further arguments to support the claim that there are good reasons why children ought to have a legal right to information about their genetic parents, that is, reasons that support interests sufficient and appropriate to generate the right in Article 7 of the CRC.

Adoptees And Donor-Offspring Have A Strong Desire To Gain This Information

There is little doubt that many adoptees and donor-conceived children want to know something about their genetic parents and family and that they have sought this information under the paradigms of both closed adoption and anonymous gamete donation. Their desire to obtain information about their genetic parents has seen adoptees and donor-conceived children actively engage in online searches. It was for this reason that the Donor Sibling Registry was set up. This website currently claims an active membership of 31,789.146 Clearly, there are some donor-conceived children already searching out this information for themselves, because they want to know.

Furthermore, children were searching for their genetic parents even under condition of closed adoption and anonymous gamete donation. In other words, adoptees felt such a strong need to know about their genetic parents that even closed adoptions and anonymous gamete donations did not prevent them from doing so. In fact, research carried out on 41 adopted persons’ searches for their genetic parents by Mark Simpson et al. suggests that the vast majority (94%) of the adoptees in their study attempted an independent search for their

146 Donor Sibling Registry, nd, np.
genetic parents prior to the paradigm shift to open adoption. Secrecy with regard to access to information about their genetic parents may have frustrated adoptees’ attempts to further their interests in this regard, but it did not always prevent them from gaining the information they wanted, if they were resourceful enough.

Indeed, the greatest challenge to closed adoption was the many requests from adoptees for information about their genetic relations. According to the Australian Institute of Health and Welfare, 2010, there was 2,903 applications for information about genetic families between 2009 and 2010 in Australia alone. The majority of these applications (72%) were made by adoptees. Furthermore, it should be noted that the number of vetoes lodged each year against the release of contact and identifying information is declining. This allows for more contact between adoptees and their genetic parents, which allows for greater information flow between genetic parents and their children.

The interest among adoptees to gain information about their genetic family is indicative of their dissatisfaction with the system of closed adoptions. “A clear majority of the adoptees who participated in the review [by the New South Wales Law Reform Commission (1990), which I discuss further in the next chapter] were in favour of the information rights given under the Act [Adoption Information Act 1990].” In addition, the Willis Report into closed adoption noted “a significant proportion of adoptees have a deeply felt emotional and psychological need to know about their origins.”

To indicate the extent of desire for this information among some adoptees, in an unprecedented case, according to a report in the National Law Journal by Tresa Baldas, one 17-year-old boy (known as Minor J in court records) was so anxious to know the identity of his father that he sued his mother in Macomb County Court in Michigan in 2006 to obtain this information. While this case was not resolved in court due to the mother insisting that the father’s named on the birth certificate was the genetic father, despite DNA tests to the contrary, it does show the extent that some children are prepared to go to for this information.

---

147 Simpson, Mark et al., 1981, p. 432.
149 Ibid., p. 33.
150 Ibid.
151 Ibid., p. 36.
152 New South Wales Law Reform Commission, 2002(b), 5.74.
153 Ibid., 6.20.
155 Macomb County Court, Michigan, 2006, np.
Of course, not all adoptees and donor-conceived children are searching for information about their genetic parents. One reason why donor-conceived children and adoptees may not be searching in greater numbers for their genetic parents is that they do not know that they are adopted or were conceived by donor gametes. Consequently, the number of seekers may rise following bans on anonymous gamete donation and following the move to open adoption.

While it is recognised that adoptees and donor-offspring are seeking information about their genetic parents, many are older when they do so. According to the Australian Institute of Health and Welfare, “Approximately four in five (82%) adoptees seeking information were aged 35 years and over.”\textsuperscript{156} This suggests that there is an increasing desire on the part of adoptees as they get older to gain information about their genetic parents. Sometimes adoptees leave it until adulthood to search because they do not want to upset their adoptive parents; they may even wait until their parents are deceased.\textsuperscript{157}

On the other hand, they may not search for their genetic parents until later in life because they were not informed of their adoption or donor-offspring status until later in life. Whatever the reason for the delay, there is clear evidence that many adoptees and donor-conceived children want this information at some stage in life and are seeking it out, whether the adoption and gamete donation allows for access to information or not.

As a psychiatrist and an adoptee, Robert Andersen understands what it is like to be without information about his genetic family background and the psychological affects that it can have on an individual. In his paper, \textit{Why Adoptees Search: Motives And More}, he relates his personal experience of being an adoptee: “I seem to have a compelling need to know my own story. It is a story that I should not be excluded from since it is at least partly mine, and it seems vaguely tragic and some-how unjust that it remains unknown to me.”\textsuperscript{158} Some people not only want to know who their genetic parents are, but they seem to have a sense of injustice about being deprived of this information, which they feel is rightfully theirs. One reason for this need for information may be due to feelings of abandonment and the search for self—who am I?

\textsuperscript{156} Australian Institute of Health and Welfare, 2010, p. 33.
\textsuperscript{157} New South Wales Law Reform Commission, 2002(b), 5.74.
\textsuperscript{158} Andersen, Robert, 1988, p. 18.
Abandonment Issues

It has been suggested by Nancy Verrier, a psychotherapist and adoptive mother, that abandonment issues could be one of the prime motivators for adoptees searching for their genetic parents.\(^{159}\) It may be that telling a child that she is adopted, for instance, creates feelings within the child that she was unwanted by her genetic parents, which could lead to feelings of abandonment and a sense of personal worthlessness. Although many adoptees are loved by their adoptive parents, some may still have a strong need to know their genetic parents in order to lay to rest feelings of abandonment and to learn firsthand the reasons for their adoption. Of course, it is recognised that there may be other issues besides abandonment that apply to adoptees; they may feel a sense of loss for their parents, for instance.

However, it is not only adoptees who feel a sense of abandonment, some donor-conceived adult also seem to experience feelings of abandonment, according to a study by psychologists J.E. Scheib et al.\(^{160}\) Based on Scheib’s study, problems for donor-offspring adults include: “feeling negatively distinct from one’s family, mistrust of family, a sense of abandonment by the donor and DI [donor insemination] practitioners, and frustration and feelings of loss because of the lack of information about and access to their donor.”\(^{161}\) While it may take more for some children to completely alleviate feelings of abandonment due to their adoption and donor-offspring status, information about their genetic parents could possibly help improve the situation for them. However, adoptees and donor-conceived children also seem to be searching for their own stories—their sense of self.

Narrative Identity

I understand the search for self to relate to a person’s narrative account of who they are—their narrative identity. I take the narrative account of self to relate to the stories we tell about ourselves; our lives; our families; our friends and jobs etc. Sometimes we write down our own stories often as a narrative account of our lives in the form of an autobiography. Although in some instances, autobiographies are embellished to make them more entertaining for audiences, the authors invariably know the truth. Of course, it is also true that people’s memories are notoriously unreliable. So, that sometimes it is possible that even autobiographers do not invariably remember the whole truth about their lives. Nonetheless,

\(^{159}\) Verrier, Nancy, 2011, np.
\(^{160}\) Scheib, J.E. et al., 2003, p. 1117.
\(^{161}\) Ibid.
generally speaking, people remember the important parts of their own life stories when they are not affected by memory loss or mentally incapacitated.

More often than not, it appears that when people search for their origins they are attempting to fill in the blanks, make corrections to and, in the cases of children denied information about their genetic origins until later in life, rewrite their own stories. A need to know or fill in the blanks in their narrative identity may be a contributing factor to children’s need for information about their genetic parents.

The Psychological Search For Self

The psychologist David Brodzinsky, professor of developmental and clinical psychology and director of the Foster Care Counselling Project at Rutgers University, and his colleagues focus their research “primarily on issues related to the adjustment of adopted and foster children and their families.”

According to Brodzinsky,

The search for self is universal and ongoing. For adoptees and nonadoptees alike, an understanding of the self is one of the primary tasks of psychological development. Our sense of who we are is influenced by every experience we have; it’s changed each time our life circumstances change. And it’s not just major life events—birth, death, marriage, adoption—that have an effect on our sense of self.

If our search for self is universal and ongoing, that in itself could partly explain why adoptees and donor-offspring are searching for their genetic parents. This information lends itself well to their understanding of who they are. According to one adoptee (case 354 from the NSW Law Reform Commission’s report in 2002), “We all find that fitting that last piece to the jigsaw of our natural family background, completes our personalities. With this change in legislation we can now go through life knowing we have ‘found’ our true identity.” (I discuss the change in legislation to open adoption in the following chapter). Clearly, knowing something about their genetic family background is important to some children for identity reasons. Discussion on identity will be a continuing theme in the chapter on donor-conceived children.

162 Alliant International University, 2010, (np).
163 Brodzinsky, David et al., 1993, p. 13.
164 New South Wales Law Reform Commission, 2002(a), 5.81.
The Possibility Of Suffering Genealogical Bewilderment If Denied Information Until Later In Life

It is now widely accepted that adopted children are over-represented in psychological clinics. For instance, the psychologists Nola Passmore and her colleagues, who have carried out research into adoptions, found that “fewer adult adoptees were classified as secure compared with their non-adopted friends.”\textsuperscript{165} Their study also found that adoptees were more likely than non-adoptees to be “categorised as preoccupied or fearful.”\textsuperscript{166} In addition, “Compared with non-adoptees, searchers were less confident in self and others (i.e., less secure) and reported higher levels of discomfort with closeness, preoccupation with relationships, and a need for approval.”\textsuperscript{167}

Brodzinsky et al. found in their studies that “Children who are placed later in childhood are more likely to experience acute adoption-related distress.”\textsuperscript{168} These children are more likely to know one or both of their genetic parents, so this situation is not one that my proposal could benefit. However, Brodzinsky also advises that adoption-related distress is also likely to be felt by “adoptees who are not told of their adoption until much later than the norm.”\textsuperscript{169}

If Brodzinsky is correct, then withholding the identity of a child’s genetic parents until later in her life could lead to the child suffering identity problems, or what is termed ‘genealogical bewilderment’. Genealogical bewilderment, a phrase attributed to the British psychiatrist E. Wellisch in 1952,\textsuperscript{170} has been identified in adopted children who “feel cutoff in their history—from their birth parents, their extended birth family, their awareness of their genetic inheritance, and sometimes their ethnic or racial origins.”\textsuperscript{171} These children suffer a sense of confusion about who they are. This is especially so in overseas adoption cases, where “Issues of identity can get confused for youngsters who look one way and are raised another.”\textsuperscript{172} This sense of confusion was experience by Trevor, a ten year old, who was adopted from Korea as a baby. Trevor explains,

> It’s weird being part of something you don’t know about. When we had to do a family tree in school, I didn’t know what to do. I wondered whether I should have

\textsuperscript{165} Passmore, Nola, Feeney, Judith & Peterson, Candida, 2005, np.
\textsuperscript{166} Ibid.
\textsuperscript{167} Ibid.
\textsuperscript{168} Brodzinsky, David et al., 1993, p. 84.
\textsuperscript{169} Ibid.
\textsuperscript{170} Sants, H. J., 1964, p. 133.
\textsuperscript{171} Brodzinsky, David et al., 1993, pp. 13–14.
\textsuperscript{172} Ibid., p. 99.
included my Korean parents. I certainly look more like them than my parents now.\textsuperscript{173}

Genealogical bewilderment is a sense of disconnectedness from their past that many adoptees feel and also many donor-conceived children.\textsuperscript{174}

However, according to Brodzinsky, “For most adoptees, bewilderment is not a chronic condition. It is a sense of confusion and alienation that seems to emerge at critical times in a person’s development.”\textsuperscript{175} He further explains,

As the school-age child begins to understand the logical implications of adoption, he starts to feel a sense of loss for the parents, and the family, he never knew. Even if he was adopted as an infant, even if he never met his birth mother and has no recollection of her, he still experiences—at least to some degree—a sense of loss; he still grieves.\textsuperscript{176}

Although it is not a chronic condition, genealogical bewilderment includes a sense of loss even when the adoptees did not know their genetic parents. Furthermore, according to Brodzinsky, grief for the adoptee can be slight or “frequent and disturbing.”\textsuperscript{177} For some adoptees, “the lost parents often linger as ‘ghosts’ in their mental and emotional life, making it hard to come to terms with the loss.”\textsuperscript{178}

Genealogical bewilderment can also lead to feelings of mistrust in the social parents who withhold information about the genetic parents of their child from that child. Again this applies not only to adoptees but also to donor-conceived children. One donor-offspring relates,

As time went on, some of the realities of this situation sank in. I became very depressed for a while. I wasn’t the person I thought I was. And my parents, the people I should be able to trust the most in life, had lied to me for 35 years about something so vital: about who I was.\textsuperscript{179}

Mistrust in one’s parents, for instance, can also shake one’s confidence in others. This outcome has been noted by other philosophers, such as Jacques Thiroux, who notes the impact on recipients of lies,

The recipients of lies, cheating, broken promises, and theft often feel disappointed, resentful, angry, and upset, reactions that do not engender contentment or happiness. In addition, their ability to trust the offenders is diminished and may lead to a general distrust of all human relationships.\textsuperscript{180}

\textsuperscript{173} Ibid., p. 70.
\textsuperscript{174} Ibid., p. 14.
\textsuperscript{175} Ibid., p. 14.
\textsuperscript{176} Ibid., p. 71.
\textsuperscript{177} Ibid., p. 73.
\textsuperscript{178} Ibid., p. 75.
\textsuperscript{179} Kirkman, Maggie, 2003, p. 2229.
\textsuperscript{180} Thiroux, Jacques, 2004, p. 283.
Children who are led to distrust relationships may possibly end up sabotaging their own and may pass on their distrust to their descendents. Thus non-disclosure of genetic parentage until later in a child’s life could also have an adverse affect on future generations and their families. Most people do not want to be lied to. I see no good reason to think that adoptees and donor-conceived children are any different in this respect. It is because we value truth that many of us find lying and deceit objectionable.

Aside from the studies carried out by Brodzinsky and Passmore, the psychologist Maggie Kirkman’s studies also indicate that some adoptees and donor-conceived children experience feelings of confusion about who they are when they are told that their genetic parents are different from their social parents.¹⁸¹

Genealogical bewilderment is an accepted psychological condition and it was accepted by the members of the New South Wales Law Reform Commission as a valid justification for the change from closed to open adoption (the move from closed to open adoption is discussed further in the next chapter). The Commission noted:

The deeply felt emotional and psychological need to know, the phenomenon of genealogical bewilderment in adoptees, was accepted as validity for giving them the opportunity to have information previously withheld.¹⁸²

There may be many reasons for the problems suffered by adoptees, but it seems likely that at least some of their problems are related to being adopted and lacking information about themselves and their genetic families.

For this reason, it is sometimes thought that the risk of genealogical bewilderment and the shock of finding out one is adopted, or that the man one thought was their genetic father is not, for instance, may be sufficient reason for withholding this information from children and for thinking that they may not want to know. Thus it is thought by some that it may be better not to tell children that they are adopted or donor-conceived.

Adrienne Kraft’s View

It may be claimed that problems such as genealogical bewilderment and abandonment issues only occur as a result of a child being told of their adopted or donor-offspring status. For this reason some have taken the view that in order to avoid the risk of genealogical bewilderment, for instance, children should never be informed about their adoption and donor conception status. The social worker Adrienne Kraft and her associates take this view in Some

¹⁸¹ Kirkman, Maggie, 2003, p. 2229.
Theoretical Consideration on Confidential Adoptions, Part III: The Adopted Child (1985). In this work, Kraft et al. discuss the work of others, such as Brodzinsky, and conclude that it is the result of telling children that they are adopted that leads to problems for adoptees. In this work, they discuss the adopted child’s psychological development throughout childhood. They argue that “development is different for the adopted child”. They also argue that “development would be diminished or enhanced by the direct or subtle indirect involvement in an open or confidential adoption. Open adoptions appear to have the risk of serious interference at each developmental phase.” For instance, in infancy, they argue

The encouragement of contact between birth mother and adoptive mother could have a serious effect on the developing adoptive mother infant relationship. If the adoptive mother and infant are going to settle into a comfortable pattern of relating, it is important that the pair be shielded from any interference, no matter how insignificant it may seem, that would make their attachment more difficult. Of course, it is always hoped that the bonding process between an adoptive mother and her adopted child is not interfered with and, therefore, every attempt should be made to facilitate this bonding process. And if, as Kraft et al. argues, “the adoptive parents must write letters, send pictures, or meet the birth parents”, this would place additional pressure on the adoptive parents to communicate with the genetic parents—people they may not want others intruding into their personal lives. It is easy to imagine, if this were affecting the adoptive parents, that this would then impact the child. Thus there may be some merit to the view that adoptees and by extension donor-conceived children may be affected by the provision of information or meeting with their genetic parents. If we do not want to impact the bonding process between children and their adoptive and donor recipient parents, therefore, some argue, it would be better for children not to be made aware of their adoption and donor-conceived status.

Of course, in infancy and the early stages of childhood it is unlikely that children will grasp much about their adoption process. However, aside from the potential problems of bonding with their social parents that infants may face, preschool adopted children may be at risk of other problems. According to Kraft et al., “It is clear the preschool child cannot fully understand adoption and all it entails. There can be increased fears and fantasies for the adopted preschooler if not reassured by the permanence and reliability of his own relationship

183 Kraft, Adrienne et al., 1985, p. 139.
184 Ibid.
185 Ibid., p. 145.
186 Ibid.
with his parents.” Kraft et al. argue that “In open adoptions the added burden of relating to birth parents may tax the integrative capacities of a young child.” It is reasonable to imagine that a disruption to the child’s sense of permanence, reliability and integrative capacities could be triggered by information that he is adopted. With this risk to consider, telling a child at the preschool stage of life that they are adopted could be considered harmful. It would be better, therefore, not to tell the preschool child.

However, there are also problems to be encountered with informing a school child. As adopted children get older, according to Kraft et al., “development is complicated enough without introducing any potential interference. In an open adoption, what may result is a feeling on the part of all concerned that the adoption arrangement is closer to a foster placement than an adoption.” Therefore, in order to avoid introducing any further complications into the school child’s life, it is better to leave this information until later in their life or not provide it at all.

Adolescence is a notoriously difficult time for children and parents. Kraft et al., argue that during this period “open adoption creates an additional problem for the adoptive parents. If the adoption is open, and if the adolescent is going through a turbulent period, the inner conflicts will be reflected in the relationships with the birth parents and with the adoptive parents.” It is thought that should children become upset with their adoptive parents that they will seek to live with their genetic parents. Kraft et al. argue, “the availability of the opportunity to make that shift creates complications for the adoptive parents and ultimately for the adolescent's welfare, complications that would not exist had the contact with birth parent not been maintained.” If Kraft et al. are correct, then it is better that children are not informed in adolescence either. It would, therefore, seem that there is never a good time to inform children about their adoptive and donor-conceived status as at every stage of development there is a risk to the child’s psychological wellbeing and care. Indeed, it may be argued that adopted and donor-conceived children would live quite normal and happy lives without the risk of psychological problems if they were never informed of their adoption and donor-conceived status. Thus, it is understandable why Kraft et al. take the view that there are no benefits to be gained from telling children about their adoptive and donor-conceived status because telling them only risks harm to them. Their conclusion is that “There is no inherent

187 Ibid., p. 146.
188 Ibid., p. 147.
189 Ibid., p. 148.
190 Ibid.
191 Ibid.
benefit in such knowledge. To the contrary, there may be definite risks for the child at each phase of development.” The aim, of course, is to ensure that children do not suffer any more harms than they necessarily have to as a result of their adoption or donor-offspring status. If this could be achieved by withholding information about genetic parents, then it is clear that we should support Kraft’s argument.

Problems With Kraft’s View

However, there are some problems with Kraft’s view. In the first place, Kraft is mistaken in assuming that there are no benefits to children having this information. As was previously noted, there are benefits to children having this information and risks to them if they do not have it. For instance, there is the benefit of increased autonomy when children can identify who they are related to for the purposes of healthcare or reproduction and the risk of reduced autonomy if they never have it.

In the second place, there are the risks of psychological problems if they are denied this information. Of course, if Brodzinsky is right, some children only face this problem if the information is withheld for too long and then disclosed. However, the problem for Kraft’s view is that the possibility of maintaining such a secret over a person’s life time is quickly dwindling. Secrets are notoriously difficult to keep and exposure is always a threatening possibility. To keep such a secret as a child’s adoption throughout that child’s life would be difficult because, no doubt, there would be others who would know this information besides the adoptive parents. According to the Post Adoption Resource Centre (PARC), which was established to provide counselling and advice for people affected by open adoption, it is “clear that with or without the change of legislation the concealed adoption will always be a time bomb waiting to explode.” This being the case, unless Kraft has discovered a method whereby it can be guaranteed that children will never find out, it is risky to withhold this information from them for long periods of their lives, given the risk of psychological problems for adoptees if the information is only disclosed later in their lives.

While there may never be, according to Kraft et al., a good time to inform children of their adoption and donor status, there are good reasons for thinking that the information should be provided before there is a risk of problems occurring. As has been discussed, autonomy is compromised when we withhold this information and there are potential risks to

---

192 Ibid., p. 150.

193 New South Wales Law Reform Commission, 2002(b), 5.77.
health, risks of incest occurring and reproduction risks. Therefore, it seems to me that Kraft et al. are somewhat mistaken, first, in thinking that there are no advantages to having information about genetic parents and, second, in being too optimistic in thinking that children will not find out this information at some later stage with the added risks of suffering psychological problems and feelings of distrust and resentment of their social parents for deceiving them. Denying children information about their genetic parents runs health risks and cannot be justified if there is a possibility of them finding this information out at a later age, which leads to the added risk of genealogical bewilderment.

Of course, part of the problem that has led to this sort of thinking is that many people regard a child’s past identity as something that can be manipulated, changed or altered to suit the desires of others. According to Pauline Ley, an adoptee who established the Geelong Adoption Programme in the 1980s, a support and advisory group for those affected by adoption, it was believed that a child’s genetic identity could be hidden and a new identity created for an adopted child, one that would treat the genealogical history of the adoptive parents as that of the adopted child.\footnote{Ley, Pauline, 1992, p. 101.} It was (and perhaps still is) believed that children’s own genetic identity counts for very little and that any identity can be attached to the adopted and donor-conceived child without it having any affect on the child.

Clearly there are problems with this view, since children are suffering problems of genealogical bewilderment when they find out they are not who they were told they were. A need for information about their genetic identities has led a number of adoptees and donor-conceived children to search for information about their genetic parents. These searches seem to have impacted state governments in Australia to such an extent that there was, as we will see, a paradigm shift from closed adoption to open adoption and to a number of states banning anonymous gamete donation. I turn to the issues of children being denied information about their genetic parents, even in cases of open adoption and anonymous gamete donation, in the following two chapters.

However, there may be other ways to counteract the problems of genealogical bewilderment and shock than resorting to denying a child her right to information about her genetic parents and deceiving her over her lifetime about who she is. The right to an identity is an important right. This is the view of some philosophers, at least. It is the view of philosopher and lawyer Michael Freeman, for instance. On Freeman’s view, “There can be
few more basic rights than a right to one’s identity”\textsuperscript{195}, which seems to ring true to me. Who we are, our identities, provides us with the means to negotiate the world and people within it, providing us with the means to communicate to others something about ourselves, who we are, grasped from the pieces of our history that we tend to narrate in the form of a story. The truth about who we are may be painful to accept, but finding out one was deceived over a number of years by those we place trust in would be just as shocking and painful. More importantly, the problem with withholding information about health can be life-threatening and this is the greater risk.

\textit{Counteracting The Problems Of Genealogical Bewilderment And Shock}

The stories related by donor-offspring and adoptees suggest that there is something important about having the facts when it comes to information about who we are, where we came from, and how we came to be in the world. Usually this information is received from one’s genetic parents when one is raised by them. However, when children are not raised by their genetic parents they may be deceived about their identities. If denying a child information about his genetic heritage until later in life leads to that child suffering genealogical bewilderment or shock at the disclosure, then it seem to me that it would be better to provide the child with the truth about their genetic identities from an early age, rather than leaving it until these problems become risks. Providing children with the correct information about their genealogy at an early age allows them to easily assimilate that information into their narrative account of themselves. This would provide them with a coherent, consistent narrative identity over time, thus preventing the risk of genealogical bewilderment and shock. This would seem to me to be in the best interest of the child.

Of course, adoption-related problems due to adoptions that take place at later ages may be unavoidable, since society has little control over the age at which a child is placed for adoption. However, adoption-related problems due to not being informed of one’s adoption status until later in life when disclosure could be harmful could possibly be prevented through early disclosure. As the exact age for disclosure of who one’s genetic parents are is not the topic under discussion, the question I am seeking to answer is if children should have the right to information, not when they should be told, I refrain from providing too much discussion on this topic. However, as a result of seeking to prevent harms to children, and to show why genealogical bewilderment was considered by the NSW Law Reform Commission

\textsuperscript{195} Freeman, Michael, 1997, p. 196.
as one of the justifications for instituting open adoption, this affect on children’s sense of identity, through only finding out about their adoption status later in life, is cause for concern and should necessarily be taken into consideration.

In order to prevent or minimise harms to children, genealogical bewilderment is one justification for instituting open adoption because it can impact a child’s sense of identity. Genealogical bewilderment is cause for concern and should necessarily be taken into consideration when bearing in mind the right in Article 7 of the CRC. Of course, counselling ought to be made available to social parents faced with the difficult task of informing their children about their genetic parents. One would think this should go without saying, given the psychological impact disclosure of this information could have on older children, but counselling for children should also be made available when receiving this information in order to minimise the impact on them. How the information is presented to the child would obviously play some part in the impact the information has on the child. After all, the risks of shock or genealogical bewilderment could be dependent on whether or not the information is delivered with the sensitivity required to address a child’s feelings about themselves.

**Conclusion**

Children are driven to find out information about their genetic families if they discover or are informed that they are adopted or donor-offspring. This need to know may be driven by a deep desire to fill in the gaps in their narrative identity. Denying children information about their genetic parents can have a psychological impact on them if they only find out later in life that they are adopted or the result of gamete donation. Genealogical bewilderment is one condition that can affect those who are not informed until later in life about their genetic parentage, shock is possibly another. While withholding this information is an option, it is not a justifiable one given the possible risks to children’s wellbeing; harms that could potentially be avoided by providing information to children on their genetic parents from an early age. Psychological risks to children who are denied information about their genetic parents until later in life are a concern and ought to be given due consideration in the discussion on whether or not children ought to have the right to information about their genetic parents. If current accounts on these risks are correct, then information about genetic parents should be given to children early in life to make it easier for them to assimilate that information into their narrative account of themselves. Early disclosure can provide children with a consistent account of their narrative identity over their remaining lifetime.
Adoptees and donor-offspring are most vulnerable to being denied information about their genetic parents—the problem addressed by Article 7 of the CRC. I take up the issues of adopted children in the next chapter and donor-conceived children in chapter 6.
Adopted Children

The most discussed people regarding information about their genetic parents are adoptees. In this chapter, I discuss the various arguments that have been presented by adopted persons in pursuit of information about their genetic families as presented by the *Willis Report* and the *New South Wales Law Reform Commission Report* into adoption practices. I include discussion on the reasons why Australia has moved away from secret adoptions to openness about the adoption and the identities of the genetic parents of adopted children. Adopted persons are included among the children my thesis seeks to represent as those who should have access to information about the identities of their genetic parents. This is because until relatively recently, adoption in Australia was a closed matter. A child was placed for adoption and in some cases, information about her genetic parents was not recorded, or if it was, the records were kept secret. Under this norm, a number of children were not informed that they were adopted. Some think this was a good thing for the children, their genetic parents and their adoptive parents. It was thought that adopted children, who were never informed of their adoption status, would be less likely to be affected by the stigmatisation of being adopted, for instance.

In contrast to closed adoption, open adoption, as it has come to be known, is an open event whereby information about the genetic parents is retained and is available to adoptees on request. The move to open adoption addresses some of the previous noted risks and benefits and is more in keeping with Article 7 of the CRC.

The crucial aspect of open adoption that I defend in this dissertation is the availability of information about an adopted child’s genetic parents that the child can access on request. It does not include the additional argument for contact between genetic parents and their adopted out children. However, recognising that the availability of this information may create problems for some adoptive and genetic parents, I include discussion on how this can be avoided.

Adoption Statistics In Australia

According to the most recent Adoption Report compiled by the Australian government, there were 412 adoptions in Australia during 2009–10.\(^\text{196}\) Of the current 412 adoptions, 31% (127)
were “known” adoptions; that is, the children were adopted by people who knew them. 197 Local adoptions (those of Australian children unknown to their adopters) made up 15% (61), and the remaining 54% (222) were overseas adoptions of non-Australian children. 198 From these figures, a clear majority of adoptions in Australia in recent years were for overseas children. As we will shortly see, the type of adoption in Australia is relevant to the accessibility of information about genetic parents for certain adoptees, even in the case of open adoption. However, before we get to that, I begin with a brief account of legal adoptions in Australia.

**The Introduction Of Legal Adoption**

Prior to the late 19th century, adoption in Australia was not a legal matter. Children could be relinquished to institutions or given to another couple without going through any legal formality. At the time, children relinquished to an institution or workhouse became wards of the state. According to Cate O’Neill on the government website *Find and Connect*, looking after these wards of the state was costly for the government, and so a move to place these children in permanent caring homes led to the institution of legal adoption.199

Legal adoption commenced in Western Australia in 1896 with the introduction of the *Adoption of Children’s Act 1896*. 200 Similar legislation soon followed in other Australian states. 201 In its most general form, legal adoption is the process by which the legal rights and responsibilities of a child are transferred from his birth parents to his adoptive parents. 202 Thus adopted children become, by law, the responsibility of their adoptive parents and cease to be the legal children of their genetic parents. 203 This means that adoptive parents acquire legal rights of custody and guardianship from genetic parents (or legal guardians) who are deemed to surrender their rights on the legal adoption of children. 204 Legal adoption results in the adopted child having two birth certificates—her original one with the names of her genetic parents and the new birth certificate with the names of her adoptive parents in place of her genetic parents. 205

---

197 Ibid., p. 12, 2.1.
198 Ibid. Figures may not add up to 100% due to rounding.
199 O’Neill, Cate, 24/02/2009, np.
200 Higgins, Daryl, 2011, np.
201 Ibid.
203 Ibid.
204 Ibid.
The aim of legal adoption is to provide a child with the care and nurturing it needs to grow when its genetic parents are unable or unwilling to do so. Of course, adoption can provide parents who may not be able to reproduce offspring of their own with a child. However, the current primary aim of legal adoption is to provide a home to a child in need of such. For, according to the first two principles of the Western Australia Adoption Act 1994, “The paramount considerations to be taken into account in the administration of this Act are (a) the welfare and best interests of the child who is an adoptee or a prospective adoptee and (b) the principle that adoption is a service for a child who is an adoptee or a prospective adoptee.” Of course, this may not have been the case in 1896 when legal adoption was introduced—other reasons may have taken precedence, such as the reduction of welfare costs for orphans. Because there was little or no support for unwed mothers at this time and many had to place their children in orphanages as a result of being unable to care for them, it is easy to imagine that overcrowded orphanages posed a problem for the children, carers and the state that had to support them. Under these conditions, it is understandably that the carers in the orphanages and the state would be eager to reduce the numbers of children they had to look after and support. The prospect of adopting out these orphans legally to ‘good’ parents would be greatly welcomed by all concerned. Besides the benefit to the state, children would also benefit. For instance, children would be looked after individually as opposed to being one of many in an orphanage. It was also hoped that they would be better looked after by their social parents, given the little individual attention that could be afforded by the orphanage carers. However, the greatest advantage to the child was that she would be given a home from which she could not be removed by her genetic parents, if they decided at some future time to reclaim their child. However, legal adoption did not seem to provide the necessary requirement to make this new legal family of the adopted child completely comfortable with their new family status. For at this time, there were other considerations involved with adopting a child—there was the shame associated with being born out of wedlock. There may also have been a stigma attached to caring for a child born out of wedlock. This would, no doubt, have put some families off adopting children.

As a result, within a short time, legal adoption developed into a secret affair with the introduction of the Adoption of Children Act 1965. Closed or secret adoptions, as they are known, were “seen as the solution—[to the shame surrounding pregnancies out of wedlock

206 Ibid., 2002(c), 2.6.
208 New South Wales Law Reform Commission, 2002(b), 2.7.
and the stigma attached to adopting a child] where the birth identities of adopted children were effectively erased to allow the children’s identification with their new adopted family.”209 While this solution solved some of the problems associated with adopting a child, effective erasure of adoptees’ identities, as we will see, led to some adopted children never finding out that they were adopted and others only finding out later in life, sometimes only after the death of one or both of their adoptive parents. Withholding this information, as has been shown, can lead to risks for children. However, at the time, these problems were not understood, because few studies if any had been carried out on the affects of adoption on children. Despite this lack of research, there were perceived benefits to closed adoption when it was originally introduced.

**The Benefits Of Closed Adoption**

Originally there were good reasons for instituting closed adoption into law. For instance, there were benefits for both genetic and adoptive parents and adoptees as noted by the New South Wales Law Reform Commission (a government body charged with proposing changes to the general law in New South Wales) in its report in 1992 on open adoption. It noted the following benefits that were thought to be gained from closed adoptions and reasons why Australian society in the past chose secret rather than open adoption.

1. Secrecy protected a child against the stigmatisation of being born out of wedlock. The terms “illegitimate” and “bastard” referred to such children,
2. Secrecy protected the confidentiality of adoption information,
3. Secrecy protected adopted persons from public knowledge of their illegitimacy,
4. Secrecy prevented birth parents from interfering with the adoptive family or from trying to reclaim the child,
5. Secrecy protected the adoptive parents from the shame of their infertility,
6. Secrecy allowed the adoptive family to maintain the appearance of a “traditional” family,
7. Secrecy protected the identity of the birth mother.210

During the era of secret adoptions, many single mothers were sometimes encouraged or forced to give up their children for adoption in order to avoid stigmatisation of themselves and their children due to their status as single parents.211 This option was presented to single mothers “by family members, hospital staff and social workers and no doubt many others, as the best thing to do, especially for the child.”212 Here, even in closed adoption times, there is

---

209 Higgins, Daryl, 2011, np.
211 Ibid., 5.30.
212 Ibid., 5.31.
reference to what is in the best interest of the child. Clearly, the people of that time were concerned about the best thing to do for the children of unwed mothers in order to avoid the stigmatisation association with this issue. They were also concerned about the problem of stigmatisation for the unwed mother.

Secret adoptions were also intended to help single mothers to make a “clean break”213 from their children, which was believed (and may still be believed by some) to be in the best interest of both.214 One can easily understand a single mother, who is reluctant to hand her baby over for adoption, may experience feelings of guilt over her decision. Continued contact with the child would be a constant reminder of her decision. It may have been thought better, under such circumstances, for the mother not to be constantly reminded of her child through continued contact and reminders.

In addition, closed adoption was intended to prevent genetic family members from contacting the child and the adoptive parents.215 Continued contact between genetic parents and their children may also affect the adoptive parents’ sense of security about the genetic parents reclaiming the child at some future point. This insecurity on the part of adoptive parents could, in turn, affect their bonding relationship with the child, which would, no doubt, impact the child. It is often thought that the adoptive parents should be free from outside pressures to bond with their child as genetic parents bond with their children without outside interference. Under these circumstances, it is understandable that it was considered better for all concerned if the genetic family made a ‘clean break’ with the child and for the child not to know of their existence. It was thought that the best way to do this was through closed/secret adoptions. Secret adoption would promote the clean break for the genetic mother, it would help the adoptive parents assume the role of the child’s genetic parents without ever letting the child know she was not their natural child, it would help the adoptive mother bond with the child and the adoptive parents would not have their lives interrupted by the genetic parents. Thus, for a number of reasons, closed adoption was thought to be a good thing, not only for parents, both genetic and social, but also for the adopted child.

However, in order to establish secret adoptions and to ensure that the secret adoption remained secret, the government and adoption agencies had to conceal adoption records. “All records of the adoption proceedings, including the original birth certificate, were now sealed by court order, and an amended birth certificate for the child was issued to the adoptive

213 Ibid., 5.20.
214 Ibid., 2.13.
215 Ibid., 5.31.
parents.” The new, amended birth certificate listed the adoptive parents as the genetic parents. The original birth certificate that identified the genetic parents, or the first parents of the child, if these were different from the genetic parents, were sealed. In many jurisdictions, following these steps, adopted persons could no longer request their own original birth certificates without an order from the courts. These measures were meant to ensure that adopted children were never informed of their adoption status. It was expected that closed adoption would lead adoptees to believe that they were the natural children of their adoptive parents, thereby avoiding many of the problems associated with illegitimacy. However, there were problems with this choice of solution to the problems associated with adoption.

**Some Problems With Closed Adoption**

Naturally, because of the policy of secrecy, many adoptive parents did not inform their children of their adoption status. As a result, many adoptees are without information about their genetic parents, or this information is limited to those who know their adoption status (such as older children) or to those who find out and are resourceful enough to obtain information for themselves. However, those not resourceful enough are without information about their genetic family medical history and their genetic siblings and half-siblings and live unknowingly with false information about themselves—that their social parents are their genetic parents, for instance. Many adoptees and their genetic parents were dissatisfied with the secrecy arrangements, which led in part to the *Willis Report* in 1989 and the *New South Wales Law Reform Commission Report* in 1990 and eventually to open adoption.

Under the CRC, the practice of secret adoption is frowned upon, because it is seen to deny children information about their identity to which the CRC stipulates they have a right. Article 8(1) specifies: “State Parties undertake to respect the rights of the child to preserve his or her identity, including nationality, name and family relations as recognised by law without unlawful interference.” Additionally, in a statement to the government of Armenia regarding its laws on secret adoption, the CRC Committee notes its concern at the practice of keeping the identity of biological parents of the adoptee secret.

---

216 Brodzinsky, David, 2005, p. 146.
218 Ibid.
219 Ibid.
221 Department Of Foreign Affairs And Trade, 1995, (np).
The adoption law should guarantee the right of the child to know his or her origin and to have access to information about the background and vital medical history of both the child and biological parents.\textsuperscript{222}

The CRC intends not only to protect the adopted child from lack of family health information, but also to preserve her original identity. The CRC Committee voiced this concern to the Russian government (2005)—the CRC Committee

Notes with concern that the right of an adopted child to know his or her original identity is not protected in the State Party. The Committee encourages the State Party to protect the right of the adopted child to know his or her original identity, establishing appropriate legal procedure for this purpose, including recommended age and professional support measures.\textsuperscript{223}

The state party—a government that has ratified the CRC—is in this case the Russian government. This is the method of address used by the CRC when addressing the governments of ratifying nations.

Here the point to remember is that the CRC Committee notes a number of problems with the practice of secret adoptions that, they argued, could be rectified through open adoption. As we have seen, the CRC Committee advises governments that have ratified the CRC about their responsibilities and its expectations of them with regard to adopted children’s right to information about their genetic parents, recommending changes to the law in order to facilitate access to information. Clearly, the CRC Committee want children to retain a sense of their genetic past, and open adoption is seen as a better way to achieve this. Closed adoption does not conform to the CRC and, therefore, does not meet the obligations of Australia’s international commitments on this issue.

There was also a concern that the law surrounding adoption was promoting dishonesty by encouraging the state and parents to lie to adoptees about their adoption status and by promoting the practice and dissemination of disinformation—according to the 1990 \textit{New South Wales Law Reform Commission Report} “One of the most distinctive features of recent thinking and practice in adoption is the view that the law should not facilitate deception or secrecy, but should promote openness and honesty.”\textsuperscript{224} Thus the move to open adoption is a move for Australia towards openness and honesty within the adoption process. A government anxious to portray itself as honest and open would be at odds with the system of closed adoption because closed adoptions place governments in the unenviable position of having to be dishonest to a particular group of its citizens. This undermines a government’s credibility

\textsuperscript{222} Hodgkin Rachel & Newell, Peter, 2007, p. 106.
\textsuperscript{223} United Nations High Commissioner for Human Rights, 2005, p. 9, Sect 40 & 41.
\textsuperscript{224} New South Wales Law Reform Commission, 2002(c), np.
in the same way that lying undermines the credibility of any member of the public. While at the same time, it shows the government to be deliberately marginalising certain members of the community, who are already disadvantaged by lack of information about their siblings, half-siblings and their genetic health status.

Furthermore, closed adoptions also force others caught up in the adoption process to be duplicitous, including other family members and friends. According to one adoptee, identified as case 361 in the New South Wales Law Reform Commission Report, “So big was this secret that all our cousins, aunts, uncles, family friends knew, but I was 33 years old before I gained the courage to write to Youth and Community Services, and find out the truth.” According to case 361, “It hurts to think that I may have died without ever knowing. I personally think that if anyone had the right to know it was me.” In a family where secrecy and closed adoption is encouraged, many relatives and friends will know about the adoption and will be encouraged to lie to the adopted child in order to maintain the family secret.

Of course, it is true that governments may have reason to lie to their citizens at one time or another, but they ought not to blatantly do so without good reason while also encouraging others (including family members) to join in the lie. Clearly, there are a number of problems with closed adoption that has left many adoptees dissatisfied with the process.

So, while in theory closed adoption sounded good; in practice there were many problems with this way of dealing with adopted children. Furthermore, social attitudes had change, which had an impact on the way people started viewed adoptions.

**Other Problems With Secret Adoption**

Above I listed seven reasons why, according to the 1990 New South Wales Law Reform Commission Report, adoption had been secret rather than open in the past. As we will see, these reasons are no longer sufficient grounds for supporting closed adoption—social attitudes had changed in the years between 1965 and 1990.

Reason (1) for past secrecy: *secrecy protected a child against the stigmatisation of being born out of wedlock. The terms “illegitimate” or “bastard” refer to such children.*

The large majority of adopted children were born to unwed mothers. One of the driving forces behind closed adoption in the past was the stigma associated with illegitimacy and

---

225 Ibid., 2002(b), 5.78.
226 Ibid.
unwed mothers. Attitudes have changed in recent years. Many contemporary Australian couples now raise children without getting married. The New South Wales Law Reform Commission Report notes this social change in Australian attitudes. Since the stigma attached to an unwed mother and her child has diminished greatly, there is no longer reason to protect the identity of either through closed adoption.

In addition, many adoptees and birth mothers were actually seeking contact with one another, which was one of the driving forces behind the move to open adoption, which was noted in the Willis Report (1989) and the New South Wales Law Reform Commission Report (1990). Since this is the case, the first argument for closed adoptions is no longer justified. The same reasoning applies to Reason (7), secrecy protected the identity of the birth mother, and to Reason (3), secrecy protected adopted persons from public knowledge of their illegitimacy.

Reason (2) for past secrecy: secrecy protected the confidentiality of adoption information. First, secrecy was not always effective at protecting private or confidential information. One adoptee, identified as case 268, said this of closed adoption: “All my life I have had a feeling that I was adopted despite my parents making every endeavour to dispute this fact”. Another adoptee, Sheila, was never told she was adopted. However, she retained vague memories of her past. She discovered, by accident, at fifteen that she was adopted. Sheila states, “I vaguely remembered my older [biological] brothers pushing me in a baby carriage. When I would ask my adoptive mother about this, she would say I was imagining things, that no such thing ever happened.”

Another adoptee, identified as case 113, stated, “I was adopted in 1952, my parents decided never to inform me of my adoptive status. I eventually found out by accident at the age of eight, but have never discussed the topic with my parents, even to this day.” These examples show that secrecy was not always effective. Adopted children sometimes found out they were adopted despite efforts at secrecy. Indeed, if an adoptee managed to find out that there was ‘secret’ information about her birth, this knowledge may have further piqued her curiosity and encouraged her to seek out that information.

Nor did secret adoption prevent adoption information from becoming public knowledge. Many people in a family and many friends of the family also knew the child was adopted. It

---

227 Ibid. 2.15.
228 Ibid., 5.78.
229 Brodzinsky, David et al, 1993, p. 56.
230 New South Wales Law Reform Commission, 2002(a), 5.78.
is very hard to maintain secrecy when people have memories of their past or others know about it. Thus Reason (3), secrecy protected adopted persons from public knowledge of their [status], is also no longer a good argument for secrecy, on grounds of ineffectiveness. To be sure, there are likely to be many cases in which secrecy is effective in keeping information about an adoption confidential and hidden from public view. Would closed adoption be justified in those cases? This has to be decided based on the aim or purpose of the secrecy. If it is to protect the child and mother from stigmatisation, the answer is no, since the risk of this problem occurring is diminished in Australia now with people openly expressing their desire to adopt children. Indeed, there may even be some status attached to adopting a child now, given the few children there are available for adoption in Australia—lucky are the few who do manage to adopt a child.

This takes us to the three remaining reasons for secrecy in adoption. Reason (4): secrecy prevented birth parents from interfering with the adoptive family or from trying to reclaim the child. Open adoption has removed many of the reasons why a birth parent might try to reclaim his or her child. In open adoption, the birth mother can actively participate in the adoption process, in many cases choosing the family who will adopt her child.231 Some genetic parents may choose open adoption with the intention of maintaining a future relationship with their children. Some may even see open adoption as a collaborative process between all persons affected by the adoption, with the child’s best interests at the core rather than just reflecting the interests of the adoptive or birth parents. Furthermore, adoptive parents should have no fear of losing their children to the genetic parents if it is a legal adoption and they are looking after the child well, since the adoption process is binding. Furthermore, there is no evidence to support the fear that genetic parents would try to reclaim their children. Therefore, Reason (4) is not a sufficient reason for adoption secrecy and denying a child his rights.

Reason (5): secrecy protected the adoptive parents from the shame of their infertility. The main arguments against open adoption were submitted to the New South Wales Law Reform Committee (1990) by adoptive parents, and one of those arguments was a concerned with the stigma of infertility that may be attached to the adoptive parents. However, while this is an unfortunate state of affairs for parents, it should be noted that infertility is known to be a very common condition among Australian couples, and there is very little, if any, stigma attached to those who are infertile or have difficulty producing offspring. An ABC Health & Wellbeing

231 Ibid., 2002(c), 7.10.
article by Shae-Lee McArthur suggests that, the vast numbers of IVF births each year in Australia is testimony to the reproductive problems that affect one in six Australian couples.\textsuperscript{232} Fear of being classified as infertile, therefore, no longer seems a justifying reason for choosing to lie to children and not disclose information to them about their adoption when so many citizens face this same challenge.

In addition, although the fact of infertility may be an embarrassing issue for a parent, this does not weigh as heavily as the harms that may impact a child if the information about his genetic parents is withheld from him for an extended period of time.

Furthermore, using children in this way to protect the infertility of parents is simply to use them as a means to another’s end. Many philosophers would find problems with this way of treating children, given that the risk of stigmatisation attached to infertility is low and the consequences of exposure of this fact leads mainly to feelings of embarrassment. Furthermore, according to McLennan, writing for the Australian Bureau of Statistics “Changes in adoption procedure over the years reflect a shift in social attitudes from one in which adoptions were regarded as providing a service for adults (childless couples and young lone mothers) to one in which the wellbeing of children has become paramount.”\textsuperscript{233} In the best interest of the child, rather than her parents, Reason (5) in support of closed adoption is no longer a good reason to deny children the fulfilment of their right in Article 7.

Reason (6): secrecy allowed the adoptive family to maintain the appearance of a “traditional” family. Adoptive parents may wish to present themselves as the natural parents of the child in a “traditional” family, meaning a family with two genetic parents. The question is whether this wish is sufficiently important to override the interests of an adopted child in knowing that she was adopted and knowing the identities of her genetic parents. Non-traditional families are no longer stigmatized as they once were. The family of contemporary popular culture in Australia can be made up of two females, two males or even a single parent without drawing any attention to itself. It may be more reasonable to suggest that there is no longer a great value placed on traditional families, as there once was. Non-traditional style families are also considered valuable. Seeking to represent oneself as something one is not and which no longer carries the high value it did, is, in my view, why the interest of the adopted child to know who her genetic parents are has overriding force here also. An adopted child is not hurt by living in a non-traditional family and is benefited in several ways by

\textsuperscript{232} McArthur, Shae-Lee, 30/05/2007, np.
\textsuperscript{233} McLennan, W., 1998, p. 33.
knowledge of her genetic origins and at risk without it. Therefore, Reason (6) for adoption secrecy should be outweighed by the interests of the child to know about her genetic parents.

**Parents Support Open Adoption**

The reasons that supported closed adoption in the past seem either no longer relevant or to be outweighed by the best interests of the adopted child. In addition, some adoptive parents have supported the move to open adoption. These parents were “seeking information on behalf of their children for many years and are pleased it is finally forthcoming.” In addition, “For many adoptive parents in favour of the [Adoption Information] Act, the access to information and/or reunions has made their job of parenting easier. They consider that it has helped their children understand themselves better and in turn has improved the parent/child relationship.” Many found “that the birthparents would not take their place as parents, but would simply be friends to their adopted children.” So, clearly there are advantages to open adoption even for adoptive parents. As has been shown, there are benefits to children from having access to information about their genetic parents and risks if they do not. Furthermore, while it is understandable that adoptees would support the move to open adoption, clearly, some genetic and social parents also support this move. While closed adoption was considered a good thing when it was initially introduced, there were a number of problems with this way of dealing with children. This resulted in a move away from closed adoption to open adoption in Australia.

**Legislation On Open Adoption**

The first move to open adoption was introduced through legislation in Victoria in 1984 and in New South Wales in 1990 with the *Adoption Information Act*. The Willis Committee (1989) (formally, the Legislative Council Standing Committee on Social Issues) had tendered a report to the Australian parliament in 1989 supporting open adoption. In that report, the Willis Committee argued that “the previous policy and practices that denied adopted persons and birth parents access to identifying information concerning adoptions should no longer be supported by law.” This move to openness was instigated by positive overseas experiences,

---

234 New South Wales Law Reform Commission, 2002(b), 5.123.
235 Ibid., 5.125.
236 New South Wales Law Reform Commission, 2002(c), 2.8.
237 Ibid.
238 Ibid., 2.24.
the strong pleas for information from adoptees and their genetic parents, and the experiences of those involved in the adoption process.\textsuperscript{239}

Supported by all political parties, recommendations by the New South Wales Law Reform Commission and the \textit{Willis Committee Report} were accepted and the \textit{Adoption of Information Act} (1990) was implemented into law.\textsuperscript{240} It should be noted that the law relative to open adoption is retrospective; that is, it supersedes the laws surrounding closed adoption.\textsuperscript{241} Thus parents who had been guaranteed anonymity were then asked to comply with a law that was not in existence when they began the adoption process. That is, even those parents who adopted children under the paradigm of closed adoption were duty bound to tell their children about their adoption status and their right to gain information about their genetic parents.

Following the introduction of the \textit{Adoption Information Act} in 1990, which came into force in 1991, the Department of Community Services (DoCS) informed those affected by the changes of their rights and responsibilities under the new Act.\textsuperscript{242} This was a necessary move on the part of DoCS as this Act was made retrospective. This Act was superseded in 2000 with the introduction of the \textit{Adoption Act 2000}, which also included provisions for the release of information to adoptees in New South Wales.\textsuperscript{243}

In 1991, the New South Wales Law Reform Commission was given the task of reviewing and reporting on the implementation and administration of the \textit{Adoption Information Act}.\textsuperscript{244} The conclusion of their investigation were presented in 1992 in \textit{Report 69 (1992)—Review of the Adoption Information Act 1990}. In this section, I draw on much of the finding of this report as it gives a good account of public opinion at the time. It has the advantage of presenting arguments from adoptees, adoptive parents and genetic parents among others involved in the adoption process.

\textbf{The National Move Away From Secret Adoptions}

In addition to New South Wales, other states and territories of Australia also moved away from secret adoptions to open adoptions. The following states and territories also have provisions for access to adoption information.

\begin{itemize}
\item \textsuperscript{239} Ibid., 2.17.
\item \textsuperscript{240} Ibid., 2.25.
\item \textsuperscript{241} New South Wales Law Reform Commission, 2002(b), 2.24-2.25.
\item \textsuperscript{242} Ibid., 2002(c), 3.20.
\item \textsuperscript{243} New South Wales Health, 2010, p.1.
\item \textsuperscript{244} New South Wales Law Reform Commission, 2002(b), 2.22.
\end{itemize}
• In **Victoria**, a major and influential review published in 1983 led to the *Adoption Act 1984 (Vic)*.\(^{245}\) This Act made many changes, including creating rights to information for adult adoptees. \(^{246}\) "There are no provisions for vetoes."\(^{247}\) "Instead, a register operates on which people can record their wishes in relation to giving or receiving information and making contact."\(^{248}\)

• In **New South Wales**, the *Adoption of Children Act 1965 (NSW)* came into force in 1967.\(^{249}\) In 2000 the *Adoption Act 2000* led to the release of information to adoptees.\(^{250}\) "Veto cannot be lodged in respect of adoption orders after 26 October 1990."\(^{251}\)

• **Queensland’s Adoption Act 2009 (Qld)** has been substantially amended, and now includes provisions for information rights (subject to veto) for adult adoptees and birth parents.\(^{252}\) This is provided under Part 11, Division 1.

• **South Australia’s Adoption of Children Act 1988 (SA)** provides adoptees with access to information in Part 2A, 27.\(^{253}\) "Information vetoes cannot be lodged on adoption orders made after 17 August 1989."\(^{254}\)

• **Western Australia’s Adoption Act 1994** also provides access to adoptees to information in Division 3, 91.\(^{255}\) "As a result of amendments made in 2003, no new contact or information vetoes are permitted to be lodged."\(^{256}\)

• **Tasmania’s Adoption Act 1988 (Tas)** allows for access to information in Section 82.\(^{257}\) Tasmania implemented contact vetoes in 1999.\(^{258}\)

• **Australian Capital Territory’s Adoption Act 1993 (ACT)** also makes provision for access to information in Division 5.3, 66.\(^{259}\) "Vetoes cannot be lodged in respect of adoption orders made after 22 April 2010."\(^{260}\)

• **Northern Territory’s Adoption Of Children Act** allows access to information under Section 58.\(^{261}\) Northern Territory has provision for contact vetoes.\(^{262}\)

---

\(^{245}\) Ibid., 2002(a), 2.25.
\(^{246}\) Ibid.
\(^{247}\) Australian Institute of Health and Welfare, 2010, p. 35.
\(^{248}\) Ibid., p.71.
\(^{249}\) New South Wales Law Reform Commission, 2002(b), 2.3.
\(^{251}\) Australian Institute of Health and Welfare, 2010, p. 35.
\(^{252}\) New South Wales Law Reform Commission, 2002(a), 2.25.
\(^{254}\) Australian Institute of Health and Welfare, 2010, p. 35.
\(^{255}\) Australian Legal Information Institute, 2010(a), Division 3, 91.
\(^{256}\) Australian Institute of Health and Welfare, 2010, p. 35.
\(^{257}\) Australian Legal Information Institute, 2010(b), Section 82.
\(^{259}\) Australian Legal Information Institute, 2011(b), Section 58.
\(^{261}\) Australian Legal Information Institute, 2010(c), Part 6, 61.
\(^{262}\) Australian Institute of Health and Welfare, 2010, p. 35.
As can be seen, every state and territory in Australia has provisions to provide information to adoptees about their genetic parents. This is evidence of a consistent move from closed to open adoption Australia wide.

Following the introduction of open adoption, adoptees can, if they choose, obtain information about their genetic parents and can access their original birth certificates on reaching 18 years of age. However, this may depend on the type of adoption that took place and whether adoptive parents are abiding by the legislation governing their state and informing their adopted children of their adopted status. Where adoptive parents withhold this information, children may not know to seek out their original birth certificate. So, while open adoption in Australia ensures to some degree that, at the very least, Australian adopted children can obtain information about their genetic parents, this requires, of course, that they know there is an original birth certificate besides their amended one. If a child is not informed that he is adopted, he may never seek access to his original birth certificate and information about his genetic parentage. Where children are not informed that they are adopted, this is a breach of Article 7 of the CRC for countries that have ratified this treaty. Furthermore, adopted children’s right to information about their genetic parents is now protected on two sides—one side by the CRC and on the other by Australia’s open adoption policy.

**What Open Adoption Involves**

In order to rectify the problems that were seen to exist in secret adoption, the New South Wales Law Reform Commission (1990) recommended that the *Adoption Of Children Act 1965* (NSW) be rewritten so that adoption:

- is characterised by openness, and is no longer shrouded in secrecy;
- conforms with Australia’s international obligations; and
- is brought into line with other areas of child law, as well as with prevailing community expectations and attitudes.

It is clear from these recommendations that the New South Wales Law Reform Commission was not only interested in more openness regarding adoption, but was also concerned about the government’s international obligations which include the rights in the CRC, including

---

263 Senate Legal and Constitutional Affairs References Committee, 2011, np.
264 New South Wales Law Reform Commission, 2002(c), np.
Article 7. Following the submission of the Commission’s recommendations, access to information about their origins by adoptees was supported in Parliament on three grounds:

1. a matter of human rights;
2. for their psychological wellbeing; (Parliament also accepted the validity of genealogical bewilderment in adoptees)\textsuperscript{265} and
3. for practical application in relation to genetic inheritance.\textsuperscript{266}

These reasons are in accord with my argument. In contrast to closed adoption, open adoption provides adoptees with access to their original birth certificates on reaching 18 years of age. Recommendations from the New South Wales Law Reform Commission (1990) include:

1. The practice of telling children from an early age of their adoptive status and providing them with non-identifying information about their birth family,
2. The making of adoption orders in situations where there is continuing contact between the children and members of the birth family,
3. Providing adoptive parents with non-identifying information about the birth family,
4. Providing birth parents with some non-identifying information about the adoptive family,
5. Providing identifying information to adult adoptees, and birth parents, about each other.\textsuperscript{267}

In the words of the New South Wales Law Reform Commission, “The underlying purpose of these changes is to promote openness and honesty, on the assumption that this will be for the long-term benefit of the children (and perhaps others).”\textsuperscript{268}

While open adoption is now the prevailing Australian norm, the degree of access to genetic parents’ information varies across Australian states due to the fact that adoption in Australia is a state, not federal, issue. So, for instance, while the state of Victoria does not recognise a veto system for contact information, it has set up a register that allows people to record their wishes regarding giving or receiving information and making contact.\textsuperscript{269}

Queensland, on the other hand, provides identifying information, but only with the consent of the person whose information is being requested.\textsuperscript{270} Thus there are limits on the degree of access to information between adoptees and their genetic parents and vice versa.

\textsuperscript{265} Ibid., 2002(b), 6.13.
\textsuperscript{266} Ibid.
\textsuperscript{267} Ibid., 3.12.
\textsuperscript{268} Ibid.
\textsuperscript{270} Ibid., p. 72.
However, there are also limits on the availability of information for certain children and, as previously mentioned; some adoptees are still living under the conditions of secret adoption. Some of these problems have to do with the types of adoption and others to do with the retrospective nature of open adoption laws. I start with the types of adoption in Australia and its effects on the open adoption process.

**Types Of Adoptions In Australia**

As already mentioned at the start of the chapter, there are three different types of adoptions in Australia: known, local and overseas adoptions. Known adoptions generally occur where children are known by their adopters, who may be genetic family members and the like, such as relatives, stepparents, or carers.271 Local adoptions, on the other hand, involve Australian born children who are adopted out to Australian families that have no genetic connection to those children and who do not know the children prior to their adoptions.272 Overseas adoptions involve the adoptions of non-Australian children from overseas countries, such as China, for instance, by Australian families.273 The type of adoption is sometimes relevant to whether or not there is information available. However, even with local adoptions, where information is available on genetic parents, some adoptive parents are not making this information available to adopted children despite the move to open adoption.

**Difficulties In Obtaining Information For Local Adoptees**

This was noted by the NSW Law Reform Commission in its 1992 report, which argued that despite laws suggesting that adoptive parents should tell their adopted children of their adoption status that this was not in actual fact occurring for all adoptees. The NSW Law Reform Commission argued, “The vast majority of adoptive parents who made submissions to the Commission said that they had told their children of their adoptive status, although a small minority said that they had not done so and claimed that their adult adopted children were unaware of their status.”274 While it is expected that parents would comply with regulations following the Adoption Information Act (1990), the committee were not convinced that all adoptees were being informed. The report concludes, “Of course, this is not necessarily so: as is well known, and was reflected in many submissions to the

271 Ibid., p. 12, 2.1
272 Ibid.
273 Ibid.
274 New South Wales Law Reform Commission, 2002(b), 5.77.
Commission, many adoptees discover accidentally and from sources other than their adoptive parents that they are adopted.” Nor was the NSW Law Reform Committee convinced that it was only a minority of adoptees that were not being informed.

Submissions to the Commission by adoptive parents who had not ‘told’, therefore, do not necessarily indicate the number of adoptees who do not know of their adoptive status. However, the persons found’ survey, and submissions to the Commission, suggest that the number is not insignificant, and may be considerably larger than generally assumed.

Clearly even with laws in place granting them the right to information about their genetic parents, sometimes adoptees are not informed that they are adopted and, therefore, may not be aware that there is an original birth certificate they can access with information about the circumstances surrounding their adoption. This is in breach of their right as expressed in Article 7 of the CRC and the Adoption Information Act.

**Difficulties In Obtaining Information For Overseas Adoptees**

However, by far the biggest challenge for adopted children in Australia with regards to obtaining information about their genetic parents comes from overseas adoptions. Most of these adopted children know nothing about their genetic parents, and it is most unlikely that they will ever be able to get any information about them. This is because many overseas adoptions are from Asian countries, in particular, China, where records of genetic parents do not appear to be as studiously kept as they are in Australia. However, even if they were, it would not help the majority of orphans adopted from China, for instance. Overseas adoptions from China are much more complex with regards to rights to information about genetic parents. This is due almost exclusively to China’s one child policy.

China introduced the one child policy in 1978 to combat problems stemming from its escalating population. Under the policy, there are heavy fines imposed for those who produce more than one living child. As a result, according to a BBC news report by Adam Brooks, many parents feel forced to forsake their firstborn if it is female in the hope of giving birth to a son. There are various reasons put forward as to why the Chinese prefer boys to

---

275 Ibid.
276 Ibid., 5.79.
278 Kane, Penny & Choi, Ching, 1999, p. 992.
279 The policy does not strictly limit all families to one child only, as China does allow certain families to have more than one child in some circumstances. Nonetheless, there is an enforced policy of one child per family in most cases.
girls, one being that boys can work harder on farms; another is that there is a direct line of descent through the male bloodline.\textsuperscript{281} Whatever the motivation, it is mostly girls and boys with perceived or actual health problems that are left on the streets.\textsuperscript{282} While we may condemn parents for forsaking their children in this way, it is preferable to drowning them, a not uncommon practice in ‘one child policy’ China according to one CBA news report.\textsuperscript{283}

United States citizen Brian Stuy, an adoptive father of Chinese orphans, author and researcher into Chinese adopted children, claims that there are approximately 250,000 children left on the streets every year in China who end up in orphanages, with almost 40,000 arriving in orphanages that do international adoptions.\textsuperscript{284} These ‘deserted’ children make up some of the 54 percent of Australia’s overseas adoptions.\textsuperscript{285}

When Chinese children are adopted by non-Chinese Australian families, the ethnicity and appearance of those children, as they grow up, will lead them to be aware that they are adopted. Yet there is likely to be nothing their adoptive parents can do to make these adoptions fully open as they cannot gain information about the genetic parents of their children. While this is unfortunate for adoptive parents and children, it shows that some adoptees in Australia may never realise the fulfilment of their right to information about their genetic families, despite open adoption laws and Article 7 of the CRC. While there may be nothing that can be done for the children of overseas adoptions, there are things that can be done to change the situation for Australian children who are placed for adoption.

However, before I get to that, I discuss some of the other problems associated with open adoption for those besides adopted children. For, despite its benefits for adopted children, some genetic parents and adoptive parents are not altogether convinced that open adoption is a good thing.

\textit{Problems With Open Adoption For Genetic Parents}

Understandably, some genetic parents who placed their children for adoption in Australia prior to open adoption were concerned about the new \textit{Adoption Information Act}. For instance, according to the New South Law Reform Commission (2002), although the majority of birth mothers were enthusiastically in favour of the \textit{Adoption Information Act (1990)}, some birth mothers expressed the view that

\begin{itemize}
  \item Stuy, Brian, 26/10/2005, np.
  \item Kane, Penny & Choi, Ching, 1999, p. 993.
  \item CBS News, 30/03/2010, np.
  \item Stuy, Brian, 23/08/2005, np.
  \item Australian Institute of Health and Welfare, 2010, p. 16, 2.2.
\end{itemize}
The law should not open up the past: that birth parents had terminated their relationships with the adoptees when they consented to adoption, and had commenced a new life, perhaps with a new family who were unaware of the fact that they had given birth and relinquished the child for adoption. For many of these birth parents, the prospect of meeting the adoptee and revealing the adoptee’s existence to family was daunting.\footnote{New South Wales Law Reform Commission, 2002(b), 5.19.} It is reasonable to expect that some genetic mothers who gave their children up for adoption during times of secret adoption would be reluctant to want to reopen gateways to their past. Having made the decision to terminate their relationships with their child when they consented to adoption, it is understandable that they would have moved on with their lives. If the genetic mother had started a new family, for instance, they would find it difficult, one imagines, disrupting their new family’s lives with admissions that they placed a child for adoption. If she had children with her new family, it would be one of their sibling/half-siblings and this would surely impact them also. In such circumstances, the fear among these objectors that they would lose their family’s love and respect if this information came out is quite understandable.

The genetic mother would also, no doubt, have to explain to the adoptee and her new family why she could not take care of the child herself. One can appreciate why, therefore, for many of these birth parents, the prospect of meeting the adoptee and revealing the adoptee’s existence to their new family was a daunting prospect for them. Therefore, the claims of these genetic parents were, rightly, also taken into consideration when the government considered the move to open adoption, given the paradigm of secrecy these adoptions took place under and the guarantee of anonymity.

It now seemed to these parents that the government, in instituting open adoption, was reneging on its promise of guaranteed secrecy.\footnote{Ibid.} When adoptions took place under the norm of secrecy many genetic parents who placed their children for adoption did so with the belief that they were making a ‘clean break’ and that they would receive no further contact from the child or his adoptive parents. Some genetic parents would, no doubt, have undertaken the adoption process because of this guarantee. When we guarantee something, it is generally accepted that we make an agreement to follow through on whatever it is we have guaranteed to do or not do, as the case may be. If the Australian government made an agreement with genetic parents, who placed their children for adoption, to keep those adoptions secret and the Australian government are thought no different in their obligations to fulfilling their
agreements than others of the general public, then it is understandable why genetic parents thought it incumbent on the government to uphold their end of the bargain. However, it now looked as though the government were reneging on their agreement with them. Understandably some genetic parents were upset by the government’s decision to now make adoptions an open event.

Response To The Views Of These Genetic Parents

While the New South Wales Law Reform Committee recognised the anxieties of these genetic parents, they considered that it was very rare, from their evidence, that contact would lead to abandonment by spouses and other family members; that the secret was sometimes already known to members of the family; and that disclosure would allow the family to discuss the matter openly.\textsuperscript{288}

The argument that contact between a genetic mother and her adopted out child would lead to ‘abandonment’ by her spouse and other family members, while acknowledged by the NSW Law Reform Commission as a possibility, was not accepted as reasonable grounds for withholding information about genetic parents from adoptees. This was due to the fact that there was little evidence to support this claim by genetic mothers. If genetic mother are ‘abandoned’ by their new families on disclosure of their adopted out child, it was thought that this was only in rare cases. Thus the risk of ‘abandonment’ in these situations was considered minimal or low. Where risks to the genetic parents are minimal or low, the rights of the child should trump those of the genetic parents regarding providing information about themselves.

On the other hand, even if the exchange of information between genetic mother and child led to her ‘abandonment’ by her new family, the NSW Law Reform Commission thought that disclosure would present an opportunity for the family to discuss the matter openly. This means that rather than the genetic mother having to maintain this secret from her family throughout her life, disclosure would allow her to open up to her new family about her past and it would grant her the comfort of not having to live in fear of the secret becoming known at some point. This is always a risk, as previously noted, given the number of people that generally know about the adoption, including other family members and friends. The NSW Law Reform Commission also raised the argument that the secret was sometimes already known to members of the family. Clearly, there are others of her family, such as parents, sisters, brothers, aunts and uncles who would know about the adoption and, therefore, they

\textsuperscript{288} Ibid., 5.55.
are a potential risk to disclosure of the information to her new family. When more than one person is party to a secret, there is a greater chance of exposure, given that some people find it difficult to keep secrets. This potential risk is always present for the genetic mother and openness might prove a welcome relief.

Furthermore, there are usually good reasons why a genetic mother places her child for adoption. It is difficult to imagine her new family would fail to understand her predicament at the time of the adoption. Even if they did not understand straight away, it is likely that her new family would come to accept the situation at some future point. Furthermore, if a genetic mother had other children with her new family, it is likely that they would want to know about their half-sibling. For reasons of the potential risk of incest, they should know. Therefore, honesty would be in the interests of both the genetic mother’s adopted out child and the children from her new family. So, while there are reasonable arguments put forward by genetic parents not to disclose their information, there are also good reasons for rejecting those arguments in the best interest, not only of their adopted out child, but also their children from her new family.

If there are no children in her new family, it is still thought better for the genetic mother of an adopted out child to be honest with her new partner. Where she cannot be, it is still thought that the provision of information about herself would be beneficial for the child. Since all that I am calling for is her identity, a genetic mother would not need to divulge anything about her past life to her new partner if she so chose. She could make this information available without informing anyone else. Of course, there is also the fear that her adopted out child could try to contact her.

It is well known that some meetings between genetic parents and their adopted out children do not go well for the child or her genetic parents. “I had a face to face meeting with my mother in 1986—a most unhappy experience for me as my mother made it painfully clear she never wanted to see me again or to have any future contact”, was the experience of adoptee case number 308 from the New South Wales Law Reform Commission Report.\(^{289}\) However, despite this bad outcome, the adoptee noted, “Even with the worst possible scenarios there have always been gains—information, background, identity and a beginning of coming to terms with the grief.”\(^{290}\) Thus even in cases where meetings between adoptees

\(^{289}\) New South Wales Law Reform Commission, 2002(b), 5.96.

\(^{290}\) Ibid., 5.95.
and their parents went badly, there are still upsides, such as gains in information and background for both.

Naturally, there are many cases where meetings between children and their genetic parents have been advantageous to both parties. For instance, according to adoptee case number 354, “I am an adopted person, and have recently made contact with my natural mother with wonderful results.”291 Despite such great results for this adoptee and her genetic mother, I remain unconvinced that it is necessary for children to make the acquaintance of their genetic parents in order to realise the fulfilment of their right as expressed in Article 7. While I am not against contact, information alone seems to suffice for the fulfilment of this right. The drive to know who one looks and behaves like could be satisfied to some extent with photographs and information. Of course, vetoes can be installed to prevent contact. Indeed, some genetic parents still do request anonymity, vetoing contact and identifying information, even in cases of open adoption. In 2009–2010, for instance, there were 74 contact and identifying information vetoes lodged.292 However, the majority (66%) were lodged by the adopted person, whereas only 28% were lodged by the genetic parents.293 Furthermore, according to the Australian Institute of Health and Welfare, the number of vetoes is declining.294 The low and declining numbers of genetic parents lodging vetoes against contact and information suggests that most genetic parents are supportive of their adopted out children having information about them.

I have no reason to believe that people will not abide by vetoes. However, it may be the case that those genetic parents lodging vetoes put them in place only as a safeguard and they may consider removing them in the future—people have, at future dates, been known to change their minds about decisions they made earlier in life. This is one of the advantages of having a veto system in place. Vetoes are a benefit for genetic parents who wish to prevent contact with their adopted out children. Since there are vetoes that can be put in place to prevent contact and since the information that I request from genetic parents can be provided without disclosure to their new families, there is no reason for denying children their right to information about their genetic parents for these reasons.

291 Ibid., 5.81.
293 Ibid.
294 Ibid.
Problems With Open Adoption For Adoptive Parents

As is to be expected, some adoptive parents were very hostile to the new Adoption Information Act. One problem for them seems to be the access to information by genetic parents. They “regarded it as involving a gross violation of their own privacy and that of the adoptees. They resented not being able to prevent personal information about themselves being released to people they considered strangers.”295 When a child is born into and is raised by her genetic family personal information about the parents is generally readily available. There is no reason to keep the parentage of the child secret in these cases. However, when a child is raised by adoptive parents, the adoptive parents may want to restrict personal information about their adoptive status to family members and close friends or, perhaps, to share it with no one. With the introduction of open adoption, information about themselves and their adopted child was expected to be shared with the child’s genetic parents—people the adoptive parents generally did not know or want to know. It is understandable that this new move to openness and provisions of information sharing between adoptive parents and genetic parents seemed to the adoptive parents as a violation of their rights to privacy. So, it is clear why some adoptive parents were not as supportive of the new Adoption Act as might be hoped.

In addition, in line with genetic parents, adoptive parents also considered the government to be “breaking a promise or contract that it made with adoptive parents at the time of the adoption.”296 If the Australian government made an agreement with social parents of an adopted child, then it only seems right that they keep that agreement. Thus the retrospective nature of the Adoption Information Act, led also to problems for adoptive parents.

It was not that adoptive mothers were against their children having a right to information per se, for, they

frequently said that they did not object to the new access to information provisions applying to adoption occurring after the Act came into operation, but thought they should not apply to adoptions which had already taken place and which were finalised when a stricter regime of secrecy was in force.297

Again, we see the same problem of making laws retrospective, only this time problems arise for adoptive parents. Retrospective laws, those laws that are introduced today, for instance, but that makes us legally bound to them from an earlier time, are difficult in some instances

295 New South Wales Law Reform Commission, 2002(b), 5.112.
296 Ibid., 5.113.
297 Ibid., 5.116.
to accept because prior to the new laws being introduced there was no legal obligation to adhere to them. Following the introduction of the new Act on open adoption, the retrospective aspect of the law makes it incumbent on adoptive parents to inform their adopted children of their genetic parents. If the adopted person does not already know, this information may strongly impact her. Of course, the opposite side of the coin is that if she is not informed until later in life adoptive parents run the risk of impacting their child’s sense of identity with the possibility she may suffer genealogical bewilderment as well as the possible risks of uninformed decision making with regards to health, consanguinity and reproduction. Despite these risks to the child, clearly there are problems with making new laws retrospective and it is understandable that some adoptive parents were upset with the new and retrospective changes to legislations regarding information about their children’s genetic parents. These new laws placed obligations on adoptive parents that they had not signed up for when they originally adopted their child. Thus they had good reason not to support the new *Adoption Information Act*.

**Response To These Views**

What seemed to bother adoptive parents the most was the retrospective nature of the new *Adoption Information Act* rather than their adopted children’s right to information about their genetic parents. The retrospective nature of the legislation is, indeed, problematic. Thus I do not argue for making the availability of information about genetic parents retrospective. However, it is recognised that while the retrospective nature of the law was problematic for adoptive parents of a child, for the government to do otherwise would create problems of inequality between adoptees—those who could access after a certain date and those who could not. Thus taking the alternative position of only informing those children who were adopted after the introduction of the new Act may have been more problematic for adoptees as it may have marginalised some. However, I do not call for information about genetic parents to be made retrospectively available to children. Therefore, the retrospective problems that occurred for adoptive parents following the introduction of the *Adoption Information Act* are avoided.

Furthermore, although it is unfortunate for those adoptive parents, who are not supportive of the new Act, to have legislation change against them in this way, clearly the government noted the benefits and risks to children of having information about their genetic parents, which grounded their justification for openness in adoption and the change in legislation that makes it possible for children to realise their right as expressed in Article 7 of the CRC.
Furthermore, their obligation to uphold the rights in this convention requires the government uphold Article 7.

Another problem for adoptive parents was the access to information about them by genetic parents. In response to this argument, as has been suggested for genetic parents, social parents have the right to lodge vetoes against intrusion into their lives by genetic parents. Furthermore, their adopted children have the right to prevent their personal information being disclosed to their genetic parents. These measures help to protect the privacy of the adopted family and their child. With these options in place, I see no reason to think that adopted children should not realise the fulfilment of their right to information about their genetic parents, should they so choose, and thus realise the fulfilment of their right as expressed in Article 7 of the CRC.

**The Benefits Of Open Adoption**

There are a number of benefits to open adoption for children and their parents. For instance, open adoption allows children and their adoptive parents to obtain information relating to genetic family health. This is beneficial information for children and their social parents to have. Furthermore, open adoption can assist children to identify their siblings and half-siblings, which is important for incest avoidance. Open adoption eliminates the dishonest and deceptive elements that accompanied closed adoption. In addition, open adoption does not deny children a part of their identities as closed adoption did. Open adoption also seeks to help preserve adoptees’ nationalities. In addition, open adoption is more in keeping with current norms, which recognise multiple types of family units including single-parent families, homosexual families and families with adopted children.

In addition, there is little if any stigmatisation attached to adoption in Australia now, reasons that pertained in the past for choosing closed adoption over open adoption. The protection of infertility of a social parent also fails to justify the need for closed adoption, given the increasing number of families turning to fertility clinics to produce their children. The claim that closed adoption allowed the pretence of a traditional family no longer seems to justify lying, deception, and the risks that pertain when information about the identities of a child’s genetic parents is withheld from her. In order to reduce harms to children and to ensure that they realise goods due them and to ensure they are not disadvantaged in some fundamental way when compared to children who are raised by their genetic parents, open adoption is perceived as in the best interest of the child, when compared to closed adoption. Parents, both genetic and social, for the most part support open adoption with only a small
number against the move. Those supportive parents perceived benefits to themselves and their children from the exchange of information.

**Conclusion**

Genetic parents who surrender their children for adoption voluntarily give up their rights to the child. Prior to open adoption, closed adoption was the norm. At the time it was introduced, closed adoption had its benefits for mothers and their offspring who were placed for adoption. It addressed the issues of stigmatisation, which an unwed mother and her children were likely to experience in an age when being an unwed mother was seen as immoral and socially unacceptable. However, there were problems with closed adoption. The most notably problem being the adopted child’s right to information about her genetic parents; as stated in the CRC. Requests by adoptees to realise this right and changes in social attitudes regarding adoption led to the *Willis Report*, which led to the *New South Wales Law Reform Commission Report* (1990) into adoption. This report recommended change to legislation regarding information about adoptees and their genetic parents. Following the recommendations of the *New South Wales Law Reform Commission Report* (1990), legislation on adoption was changed in New South Wales to allow for information about genetic parents to be provided to adoptees in that state. Other states soon followed and changed their legislation allowing adoptees to access information about their genetic parents. Although genetic parents and adoptive parents raised concerns about open adoption, these concerns did not outweigh the rights of the child to this information nor warrant withholding this information from adoptees. For, there was little evidence to suggest that the genetic and adoptive parent's fears of intrusions into their lives would be realised. Honesty within adoption is considered to be more in keeping with today’s social norms and is more in keeping with the government’s obligations to uphold the rights in the CRC, especially Article 7. So, despite objections by some genetic and adoptive parents, open adoption brings closer to realisation the right contained in Article 7 of the CRC for adoptees in Australia. Adopted children should be able to realise their right in Article 7 of the CRC in the same way that children raised by their genetic parents do. The right in Article 7 is there to protect adopted children and open adoption is better able to help them realise this right than closed adoption could, given that closed adoption was meant to prevent them from gaining this information to begin with.

Of course, as we have seen, information is not available on all genetic parents for disclosure; this is especially true of overseas adoptions and closed adoptions where
information was not retained. However, it is also apparent that even under legislation making adoption an open event, some social parents are still withholding this important information from their adopted children, even when it is available to them. However, as long as they choose this option, there is always the potential risk of exposure of their secret, especially given that other family members and friends may also be party to it. Even if the secret were never exposed, there is still the possibility the adoptee may discover the truth for herself.

While the problem for genetic mothers was one of disclosure of their past to their new families, there was little evidence presented to the NSW Law Reform Commission that this was indeed a problem. On the other hand, there is a problem for the adopted out child regarding the risk of incestuous relationships forming between her and her siblings and half-siblings. Open adoption is beneficial, not only for the adopted child, but for her siblings and half-siblings, who, it is believed, would not want to discover that they had formed a consanguine relationship with their adopted out sibling. Thus the right to access information about their genetic parents may alleviate or eliminate some of the shortfalls relating to adoptees and their siblings.

Of course, the main concern for genetic and adoptive parents was the retrospective nature of the law regarding open adoption. As I am not recommending a retrospect law be introduced, this issue is not problematic for my proposal. As there are vetoes available that can be used to prevent contact between adoptive and genetic families of adopted children, the fears of genetic and adoptive parents that the information would lead to contact and intrusion, can be laid to rest. The reasons for providing adopted children with their right to information about their genetic parents, as stipulated in the preceding chapter, are justification for trumping parents’ rights to withhold this information from them, especially so, if the risks to parents are minimal compared to the risks to the child.

However, it is not only adoptees who face the issue of being denied their right as expressed in Article 7 of the CRC, donor-conceived children are also at risk of lacking this right. In the following chapter, I address the issue of donor-conceived children and I return to the problem of narrative identity as raised by the philosopher David Velleman.
6 Donor-Conceived Children

While the most discussed people regarding rights to information about their genetic parents are adoptees, it is not only adoptees who are denied this information; donor-conceived children are also being denied this valuable information. It is because these children also face the prospect of being disadvantaged by being without information about their genetic parents that they are included among those who I argue should also be provided with access to the right articulated in Article 7 of the CRC. Donor-offspring are children born as a result of gamete donations, either of sperm, eggs or both combined with an implanted embryo. Donor conception usually occurs in three types of families: heterosexual couples with infertility problems, single mothers without partners and same-sex couples. Like their adopted counterparts, until very recently in Australia donor-conceived children too were denied information about their genetic parents. This was because, as with the paradigm of secret adoption, anonymity was the paradigm under which gamete donations took place. As gamete donations were anonymous, in many cases information about donors was not recorded. Therefore, this information, as with the case of some overseas adoptions, is unavailable to pass on to donor-offspring or their social parents.

However, in recent times and in a similar way to adoptees, there has been a paradigm shift in Australian attitudes away from anonymous gamete donation and towards more openness in relation to access to information about gamete donors. Despite this, as with adoptees, some children will not be informed of their donor-offspring status.

This is problematic from the perspective of self-knowledge and identity. In this chapter, I address the issue of access to information about gamete donors and I focus on the argument presented by the philosopher David Velleman in support of the importance of genetic ties for reasons of self-knowledge and identity, additional reasons for thinking that information about genetic parents is important for children to have. In this section, I draw on the related experiences of some of the adoptees included in the New South Wales Law Reform Commission Report of 1990 (identified by case numbers).

Australia Moves Away From Anonymous Gamete Donations

In addition to the move away from secret adoptions, there has also been a move away from anonymous gamete donations. For instance, on January 1st 2010, the New South Wales government allowed donor-offspring born after this date to access information about gamete
This is in marked contrast to the retrospective nature of open adoption. Thus gamete donors and prospective gamete donor recipients know in advance what is expected of them regarding children’s rights to information about their genetic parentage. While states and territories in Australia are responsible for their own legislation in regards to assisted reproductive technologies, four of the states (Victoria, South Australia, Western Australia and New South Wales) have legislation in place to make information available to donor-offspring. Those states and territories not covered by legislation (Queensland, Tasmania, Northern Territory and Australian Capital Territory) are covered by the National Health and Medical Research Council’s 2007 Ethical Guidelines on the Use of Reproductive Technology in Clinical Practice and Research. According to these ethical guidelines, “Persons conceived using ART procedures are entitled to know their genetic parents.” It further states, “Clinics must not use donated gametes in reproductive procedures unless the donor has consented to the release of identifying information about himself or herself to the persons conceived using his or her gametes.” As a result, the following information is now required from the donor for donor-conceived persons to access should they wish:

6.11 On request, clinics must arrange for either a medical practitioner, or an appropriately qualified health professional, to provide at least the following information, to a person conceived through ART procedures, provided that he or she has either reached the age of 18 years or acquired sufficient maturity to appreciate the significance of the request (including any implications for his or her younger siblings):

- All medical and family history information,
- Identifying information about the gamete donor, and
- The number and sex of persons conceived using the gametes provided by the same gamete donor,
- The number of families involved, and any identifying information that these siblings have consented to being released.

While this is a move more in keeping with Article 7 of the CRC, not all states have these guidelines in place. However, because the laws across Australia are not uniform in regards to donor-conceived children’s access to information, there is currently a move by the Senate Committee to introduce legislation to cover all states and territories. The aim is to introduce uniform donor conception practices legislation across Australia. The Senate

---

298 Senate Legal and Constitutional Affairs References Committee, 2011, np, 2.37.
299 Ibid., 2.2.
300 Ibid.
301 National Health and Medical Research Council, 2007, p. 25, 6.1.
302 Ibid.
303 Ibid., p. 29.
304 Ibid., p. 6, 7.65.
305 Ibid., p. 6, 7.66.
Committee proposes recommendation 9, 7.73, which includes the provisions for access to information stating: “donor conceived individuals should be able to access identifying information about their donor, once the donor conceived person reaches 18 years of age, or such younger age as agreed by all states and territories.”  This can be seen as a move to introduce a national ban on the use of anonymous gamete donations and to provide donor-offspring with access to information about their genetic parents. Thus, in addition to open adoption, there is a distinct national move away from anonymous gamete donation in Australia, which would bring Australia more in line with its obligation to uphold the right expressed in Article 7 of the CRC following its ratification of this treaty.

**The Global Move To Remove Donor Anonymity**

Donor-offspring have faced difficulties in Australia in the past when seeking to gain information about their genetic parents—information that is now considered important enough to change legislation in four states and to bring about recommendations for national legislation to be introduced. However, it is not just Australia that is making the move away from secret gamete donations. Great Britain, for instance, changed its laws in 2005 to remove donor anonymity,  and New Zealand introduced the *Human Assisted Reproductive Technology Act* (HART) in 2005 to make information available to New Zealand’s donor-conceived children.  Other countries that have also removed donor anonymity are Norway, Sweden, Austria, the Netherlands, Finland and Switzerland.  As pressure from donor offspring to know their genetic parents increases, it is expected that more countries will make the move from anonymous gamete donations to openness and honesty about this event.

The move from secrecy to openness and access to information about genetic parentage in cases of adoption and donor conception may be occurring in recognition of the fact that children would have this information if they were not placed for adoption or created from donated gametes. However, as previously argued, there are good reasons why it is important that children have this information available to them. If children are never told about their genetic parents, they run a number of risks—health being one of them. However, as in the case of early adoptions, there were good reasons for originally instituting anonymous gamete donations.

---

306 Ibid., p.xii, 7.73.
308 Department of Internal Affairs, New Zealand Government, 2011, 48(1)–49(a).
Arguments Used In Support Of Anonymous Gamete Donation

For instance, some of the arguments that were used to support closed adoptions were also sometimes used to support anonymous gamete donations. Some of these arguments, as reported by Mary Rice for the European Society for Human Reproduction and Embryology, include:

a) recipient parents of gamete donations wished to maintain the appearance that they naturally conceived the child;\(^{310}\)

b) recipient parents desired to protect the custodial father from claims of infertility and feared the adverse effects of disclosure on parent-child relationships\(^{311}\) (I return to this issue in chapter 7); and

c) the donor or donors did not want to be contacted by children born as a result of anonymous donations.\(^{312}\)

These reasons, like the reasons put forward to support secret adoptions, were provided as grounds for anonymous gamete donation. Again, these reasons were understandable when anonymous gamete donation was introduced, because at that time social attitudes about infertility and this way of acquiring a family were not as favourably looked upon as they are today. It is understandable too that sperm donors, for instance, would have fears of contact and the possibility of having to pay child support for the children that were born as a result of their sperm donations, which could amount to a great number of children at great expense to the donor.

Arguments Used In Support Of Anonymous Gamete Donation Are No Longer Justified

However, arguments in support of anonymous donation based on maintaining the appearance of a naturally formed family can no longer be justified given the different types of households that now constitute a family (homosexual and single parent and so on) without drawing stigmatisation or ridicule on parents or children (see argument for adoptees).

Donor fears that following open donations requests for child support from donor recipient parents, because they are genetic parents of the children, are not supported by any evidence that this is actually happening. While it is the case that donor-conceived children are genetically related to the donors of the egg and sperm that were used to create them and not

---

\(^{310}\) Rice, Mary, 5/07/2008, np

\(^{311}\) Ibid.

\(^{312}\) Victorian Parliament Law Reform Committee, 2010, p. 26. 3.3.2.
the social parents of the children, gamete donors, like parents who place their children for adoption, could be thought to surrender their gametes and are, therefore, in the same positions as parents who surrender their children for adoption—relieved of their rights and financial responsibility for the offspring that result from their sperm or eggs. The rights and responsibilities of the gamete donors could be considered to be transferred to the commissioning parents. Should the commissioning parents break-up, they continue to be held financially responsible for the child.

At least this was the precedent set in one case for an American child born from donated gametes (both egg and sperm) at a time when donations were anonymous. According to a report by Alexander Capron for the Hastings Centre Report, Baby Jaycee Buzzanca, born in the US through sperm and egg donation and surrogacy, found herself in legal limbo and in the unlikely position of being considered filius nulli, or the daughter of no one.313 Since Jaycee was the result of anonymous egg and sperm donation, it was impossible to identify her genetic parents. The surrogate who bore her had no genetic ties to the child and was simply commissioned to carry Jaycee to term and then hand her over to her commissioning parents, the Buzzancas. However, before Jaycee was born, the Buzzancas separated. In order to obtain child support for Jaycee from her ex-husband, the commissioning mother took the matter to court, where Jaycee was deemed to be the responsibility of neither the anonymous individuals who had donated their gametes, nor the surrogate who bore her.314 The father who commissioned her existence no longer wanted her and denied having responsibility for her because he had no genetic connection to her and was divorced from the mother at the time of Jaycee’s birth.315 In fact, this case raised the possibility that eight people could arguably be held responsible for the creation and support of this child:316 the sperm and egg donors and their partners (if any), the surrogate and her partner, and the Buzzancas.

This left the law court in a quandary about the legal parents of this child, since the normal way of identifying legal parents did not hold in this case. John Buzzanca, the commissioning father, was deemed not to be the father by the court because he was not married to or living with the mother when Jaycee was born, nor was he genetically related to the child. The court came to the same reasoning with regards to the mother—she was not genetically or biologically related to the child, and she was not in a relationship with the commissioning

314 Ibid.
315 Ibid.
316 Ibid.
father when the child was born. In the end, it seemed that this child was without a family. This case pushed the scope of the courts and resulted in a number of appeals before the decision was finally reached that the father was, in fact, John Buzzanca, who was in a relationship with the mother when the child was commissioned and intended that the child should be born; therefore, the court ruled that he was the legal father of Jaycee.  

The outcome of this case resulted in a new way to identify legal parents for purposes of financial support in cases of gamete donation, since the court held that although he did not fit the standard criteria of legal father, he and his wife did commission the child and, as such, were legally responsible for her financial support. With that landmark decision came the father’s obligation for child support. The court used the same reasoning to rule that Luanne Buzzanca, his wife at the time the child was commissioned, was Jaycee’s legal mother. Accordingly, following this landmark case, commissioning fathers and mothers could be shown to be the legal parents of a child and, therefore, liable for her financial support and not the genetic parents—gamete donors. I see no reason to think that this landmark decision would not prove useful in similar Australian cases, should the matter arise.

In addition, donors who fear contact can prevent contact of offspring by vetoing contact as in the case of adoptions. Furthermore, since the introduction of the ban on anonymous gamete donation in New South Wales and the other three states, donors are counselled on the new regulations prior to donating and the right any offspring have to information about their donors. Knowing that they are required to provide information about themselves in advance provides gamete donors with the option of whether to donate their gametes or not—providing information about oneself does not necessarily mean contact with the recipient of that information. However, to protect themselves from this possibility, donors can lodge vetoes against contact. Being provided with counselling about their obligations to provide information prior to donating, protects the rights of gamete donors to maintain their privacy, since only those willing to provide information about themselves are considered for donations. Those who consider the removal of anonymity to be an invasion of their right to privacy need not donate.

In addition, the argument that donors would be deterred from donating and that donations would drop is not supported, since there is some evidence from Great Britain that, as a result

318 Ibid.
of the ban on donor anonymity, sperm donations have increased rather than decreased.\footnote{319} This may have been unexpected, but it suggests that there is acceptance of the move away from the practice of anonymous gamete donations in the UK.

Again, the same arguments and conclusion in support of open adoption can also support open gamete donations, since in both cases children can suffer the same risks and disadvantages from closed and secret procedures and may fail to realise the advantages that children raised by the genetic parents do as a matter of course.

\textbf{The CRC And The Global Move Away From Anonymous Births}

As we have seen, there is a move away from anonymous births. This is in line with the concerns of the CRC regarding children knowing the identities of their genetic parents. In a rebuke to the Luxemburg government, for instance, concerning anonymous births, the CRC Committee stated:

The Committee remains concerned about the fact that the children born anonymously are denied the right to know, as far as possible, their parents. In case anonymous births continue to take place, the State Party should take the necessary measures so that all information about the parent(s) are registered and filed in order to allow the child to know—as far as possible and at the appropriate time—his/her parent(s).\footnote{320}

Donor-conceived children are sometimes born anonymously to their donor parents. If it does not intend genetic parents only in this instance, I take the CRC Committee to at least include them amongst its “parents” of “children born anonymously”.

In addition, according to the handbook, the CRC Committee had considered the arguments in favour of secrecy of egg and sperm donations, but had rejected them on various grounds concluding that “the law on artificial forms of fertilization, as with adoption, should be framed to protect the rights and well-being of children, not to meet the needs of childless couples.”\footnote{321} Arguments such as it is "not in the best interest of the child to know of his or her artificial conception” and that “unless their anonymity is secured donors will be deterred, fearing future embarrassment or even maintenance suits by their biological children”, were refuted due to the importance of this information for “medical reasons” and because steps could be taken by donors to prevent maintenance suits and the evidence from other countries that suggested that “donors were not deterred by being identified.”\footnote{322} These reasons

\footnote{319} Human Fertilisation & Embryology Authority, 2007, np.
\footnote{320} Hodgkin, Rachel & Newell, Peter, 2007, p. 106.
\footnote{321} Ibid., p. 106.
\footnote{322} Ibid.
presented by the CRC clearly suggest to me that the CRC intends that donor-conceived children have the right to know the identities of their gamete donor parents in countries that have ratified this agreement. Gamete donors, based on overseas statistics, are not deterred from donating by having to provide information to their donor-conceived off-spring. This being the case, then there is no reason to deny donor-conceived children information about their genetic parents and, indeed, there are good reasons to provide them with this information. Of course, it is not only the CRC who argue for information about genetic parents for donor-conceived children, others support this view and, indeed, some argue for more than the information I argue for.

**David Velleman’s Views**

For instance, the philosopher David Velleman not only supports the view that donor-conceived children should have information about their genetic parents, but he goes further to argues that they should have contact with them. In his article *Family History*, Velleman raises the concern that with the aid of current technology and the lack of a definition for the current family unit, some children do not know “by acquaintance” [that is, they have never had contact with] both their genetic parents and family.\(^{323}\) Velleman argues that alienating donor-conceived children from their genetic families is unfair because it deliberately deprives them of a good that their genetic parents most likely fully realise themselves.\(^{324}\) Since I am merely concerned with children having the legal right to information about their genetic family, I leave the issue of *acquaintance* between donor-offspring and genetic family aside, even though the same need may underlie the claim for both information and acquaintance, to focus on some of Velleman’s other claims concerning donor-offspring. According to Velleman, ancestry influences many characteristics, from appearance to aptitudes.\(^{325}\) Many adoptees seem to care about knowing who their progenitors were or knowing them by acquaintance.\(^{326}\) They go to heroic lengths to find their biological families, impelled by a deep and unrelenting need.\(^{327}\) Children of gamete donations are permanently severed from their biological past by the deliberate intentions of their custodial parents.\(^{328}\) Gamete donation severs a connection

\(^{323}\) Velleman, David, 2005, p. 359.
\(^{324}\) Ibid., p. 371.
\(^{325}\) Ibid., p. 359.
\(^{326}\) Ibid.
\(^{327}\) Ibid.
\(^{328}\) Ibid., p. 360.
that normally informs a person’s sense of identity. Basically, Velleman claims that meaning in life is importantly influenced by biological ties and that knowing one’s parents provides self-knowledge in the task of identity formation. From these premises he concludes that it is immoral to create children with the intention that they be alienated from their biological relatives—by donor conception, especially if this is of only minor benefit to the commissioning parents.

**Created To Be Denied Information about Genetic Identity**

Velleman argues that “children born through gamete donation are created deliberately by the custodial parent with the intention of creating a child whose genetic ties have been permanently severed.” Velleman states:

> Surely, we don’t believe that parents are entitled to make themselves slightly better off in some fundamental dimension by impoverishing their children in the same dimension. Why, then, should they be entitled to enlarge their own circle of consanguinity by creating children whose circle will be broken in half.

He adds, “Creating children with the intention that they be alienated from their biological relatives—for example, by donor conception, is immoral.” On Velleman’s view, it is problematic for donor parents to deliberately create children in order to increase their own family size while diminishing that of their children by denying them information about their genetic parents. If this is done in order that the parents will be in some slight way better off, then this is indeed immoral, as Velleman suggests, and, perhaps, even more so if it has negative consequences for the donor-conceived children.

**In Response To Velleman**

However, cases of donor conception vary, and only some of them fit Velleman’s description. For instance, as we will see, some parents of donor-conceived children do inform their children of their donor conception and it may not always be the case that commissioning parents of donor-conceived children are creating them in order to deliberately deny them information about their genetic parent. For instance, some commissioning parents of donor-conceived children do not alienate their children from their genetic donor relatives and, indeed, may help their child search for their donor. Wendy Kramer, for instance, set up the

---

329 Ibid., p. 363.
330 Ibid., p. 360.
331 Ibid., p. 371.
332 Ibid., p. 357.
Donor Sibling Registry in 2000 with her son because she was a sperm donor recipient and her son was curious to know who his genetic father was. Kramer set up the registry herself with the specific purpose of helping her son to find his sperm donor father. So, it is not altogether apparent that it is the intention of commissioning parents of donor-offspring to create children in order to deliberately sever those children’s ties to their genetic parents.

Furthermore, a recent study by Vasanti Jadva et al. (the first of its kind into donor-offspring) suggests that approximately 60% of donor-offspring being brought up in single parent or same-sex-parent families were told about their origins before the age of three. One reason why the majority of children in these households are informed is because it may be more difficult for those families to maintain the appearance of a ‘traditional’ family. The parents in these households will have to explain to the child the absence of a father or mother. If these statistics are correct, then clearly not all donor-conceived children will be denied information about their genetic parents. In addition, like Kramer, some parents want their children to know. In the case of single-parent household and same-sex couples, these commissioning parents may have no choice but to tell their children. However, it should be kept in mind that just because children are informed about their donor-conception status, this does not mean that they will be able to gain any information about their genetic donor parents. This is especially so where the donation was anonymous.

Arguments In Support Of Velleman

However, Jadva’s research also suggests that even in the same-sex-parent households 40% of children are not informed of their donor-offspring status, which is problematic for the reasons previously stated and it is especially so if they were deliberately conceived in order to be denied this information. If it is not in the child’s best interest to be denied information about their genetic parents, then it seems reasonable to think that it must be in the commissioning parents’ interest to withhold this information. Unless of course, the commissioning parents are unaware of the risks that could result from denying their child this rights and believe they are withholding this information in the child’s best interests. In which case, it would seem that a program informing them of the risks and the child’s rights would be in order. However, if it is in order to maintain the appearance that they naturally conceived the child, or to protect the custodial father from claims of infertility, these reasons have been shown to be no

---

333 Donor Sibling Registry, nd, np.
334 Ibid.
335 Jadva, Vasanti et al., nd, p. 3.
longer acceptable grounds for withholding this good from children and they were found not weighty enough by the CRC to deny children their rights.

Furthermore, while most donor-offspring of homosexual couples and single-parent families are notified of their genetic heritage, the case is very different for the children of heterosexual couples. If Jadva’s study is right, donor-conceived children with heterosexual parents were informed of their genetic donor origins in only 9% of cases. When a donor-conceived child is one year old, many parents claimed to intend to tell the child of her donor origins, but by the child’s seventh birthday they had apparently changed their minds. This is problematic because not telling children until later in life has been shown to be risky for a number of reasons, one of which is genealogical bewilderment and the issue of identity.

If donor-conceived children are not being informed about their genetic parents and this is in order that the commissioning parents can realise some slight benefit, then Velleman is right to be concerned. Indeed, those commissioning parents of children born as a result of both egg and sperm donation who are not informing their children of their genetic parents are, in effect, completely breaking their child’s circle of consanguinity. So, the problem, in effect, may be even greater for some children than Velleman has argued.

**Slight Advantages To Commissioning Parents**

As previously noted, any benefits to the commissioning parents of closed donor-conception, such as the covering up of infertility on the part of one or both parents, are only slight advantages in Australian culture today and, as a result, are no longer considered justifiable reasons for denying children important information about themselves, especially where there are risks to children involved. The slight advantage that may be gained by commissioning parents is that the addition of the donor-conceived child helps them to cover up the fact of their infertility. However, by covering up their infertility, they are reducing the size of the child’s family by denying the existence of their genetic family, while they themselves retain connections to their own genetic family. In other words, parents of donor-conceived children expand their family with the addition of the child. The child, by being denied information about her genetic parents, has his family reduced. The advantage to the commissioning parents is considered only slight, while the disadvantages to the child are considered great. Whatever slight advantages to the commissioning parents there are, therefore, should not

---

336 Ibid.
outweigh the already noted risks of harms (such as reduced autonomy and incest) that may befall children who lack information about their genetic parents. This is certainly in line with Velleman’s view regarding the immorality of slight advantages for the parents outweighing serious harms to the child. On this point, I am in full agreement with Velleman.

Furthermore, in line with Immanuel Kant’s maxim, in the *Groundwork of the Metaphysics of Morals* regarding what we would want to make universal laws, “I ought never to act except in such a way that I could also will that my maxim should become a universal law.”\(^3\)\(^3\)\(^8\) What Kant intends by this statement is that if we would not want to make certain of our actions into universal laws then we ought not to be acting in those ways. Clearly, we would not want to advocate a law that all children should be denied information about their genetic parents, since this information is important to them for the reasons previously stated. We especially would not want to advocate this norm for all children if there was only some slight advantage to others, such as to protect the truth of their infertility. One can imagine a world where such a law was in force and where nobody knew who they were genetically related to. Although some communities in the past lived somewhat insensitive to actual genetic heritage, these were small communities and everyone knew who was related to whom. Today, in Australia, the community is immense. If none of us were informed who we were related to, we would not be sure who was who. We would be searching the faces of others in order to find those who looked like us so as to avoid forming consanguine relationships with them or simply to get to know them. We would have no idea what genetic problems to expect or prepare for. Genealogical bewilderment would be rampant among those who felt disconnected from their genealogical past. This would be an unthinkable state of affairs, if its only purpose was some slight benefit to some citizens.

If we accept that there are good reasons for children to have this information and that the advantages to commissioning parents is only slight, then it is immoral to withhold this information from donor-conceived children.

**Self-Knowledge And Identity Formation**

However, Velleman’s main argument is that “Meaning in life is importantly influenced by biological ties” because they provide “a kind of self-knowledge that is of irreplaceable value in the life-task of identity formation.”\(^3\)\(^3\)\(^9\) In chapter 4, I discussed the importance of genetic

---

\(^3\)\(^3\)\(^8\) Kant, Immanuel, 1785, p. 57.

\(^3\)\(^3\)\(^9\) Velleman, David, 2005, p. 362.
parent’s information for a coherent and consistent narrative identity over time. Here, Velleman argues for the importance of this information for identity formation. On Velleman’s view, without this knowledge, children are deprived of one way of coming to know and define themselves. Velleman states, “This family-resemblance knowledge about myself includes information not only about how I look but also about my personal manner, my styles of thinking and feeling, my temperament, and so on.”340 Of course, this is only true if things such as feelings and temperament are the results of genetics. I will get to this issue shortly, but assuming at this point that they are, we can understand Velleman’s further statement that “If I want to see myself as another, however I don’t have to imagine myself as seen through other people’s eyes: I just have to look at my father, my mother, and my brothers, who show me by way of family resemblance what I am like.”341 When children live with their genetic parents this information is readily available to them. Children who are not reared by their genetic parents and are deprived information about them are at a disadvantage when it comes to self-knowledge and what they will be like. If Velleman is correct, not only is genetic family information important for health and the other reasons previously mentioned, but this information is also important for self-knowledge and identity formation. As previously discussed identity is an important issue in the debate concerning making information about genetic parents available to adoptees. There is no reason to think that this information is not also relevant to adopted children in the formation of their identities.

Arguments Against The Importance Of Self Knowledge And Identity Formation

However, while Velleman has a point, it could be argued that it makes more sense to believe that self-knowledge and identity formation have more to do with how we live each day, to whom we have duties and obligations, how to survive the various hazards and inconveniences that manage to seep into our everyday lives and so on. In other words, meaning for most people is about survival and getting through each day rather than what went on in their genetic family in generations past. We can imagine this being the case for people in underdeveloped nations, for instance, where the concern for most people is where their next meal is coming from and how they are going to keep their children and themselves from starving to death.

340 Ibid., p. 368.
341 Ibid.
This could indicate that meaning in life is not the same for everyone, and it may even be environmentally or culturally driven. People going through famine and drought conditions are going to be less concerned about their ancestry than those who are living a life of plenty, for instance. And, if meaning in life is not the same for everyone, family history may not have the importance that Velleman ascribes to it. It may only be of minor importance, and even that importance may be overridden by other factors such as environmental disasters of famine and drought. If identity formation is just as much related to culture and the current norms as it is to genetics, then the importance of genetic ties for identity formation has not been fully established, and genetic ties may not have the importance Velleman ascribes to them.

It could also be argued that there are other ways to gain information about ourselves without recourse to making acquaintance with our genetic relatives. For instance, we may be able to gain self-knowledge by comparing ourselves to others around us. Our close friends, for instance, may be a better mirror of what we are like than our family members. This may be so since we seem to be drawn to those around us who are most like ourselves; that is, those with whom we have common interests and who can provide a testing ground for our ideas and modes of behaviour; those we trust and those we can confide in. Our friends, culture and gender most generally reflect what we are like back at us.

Further, it may be argued that some genetic parents have not bothered to learn their family history and, therefore, would have nothing to pass on to their children other than their behaviours and characters. If that is the case, their children might not gain as much from acquaintance with them as Velleman seems to think.

**The Importance Of Genetic Ties**

Of course, there is some research to support Velleman’s position. In particular, there is research to support the claim that genetic families have similarities and do inherit similar traits. Psychology professor Thomas Bouchard, director of the Minnesota Center for Twin and Adoption Research and head of the Minnesota Study of Twins Reared Apart (MISTRA) project, has conducted studies, both medical and psychological, on twins over a number of years to investigate genetic and environmental influences on persons.\textsuperscript{342} His report on a recent study carried out on twins indicates: “There is now a large body of evidence that supports the conclusion that individual differences in most, if not all, reliably measured psychological traits, normal and abnormal, are substantively influenced by genetic

\textsuperscript{342} Bouchard, Thomas, 2004, p. 148.
factors.”343 Bouchard’s latest research seems to suggest that genetic heritability may account for a number of individual qualities, such as IQ (ranging anywhere from 22–85% from ages 5 to 50 and around 58% from 75 and older), personality traits such as conscientiousness (around 50%), artistic interests (around 40%), attitudes (above 40%), and even religiousness (above 30%).344 If this is true, then it seems that DNA can account for a large part of who we are. This would fit well with Velleman’s view of the importance of family resemblance and suggest that there is something important about having information about genetic family in order to gain self-knowledge (Connected to this is genetic essentialism, a view I discuss in chapter 9).

**Problems With This View**

However, there is some contention regarding Bouchard’s work from other psychologists. For instance, Jay Joseph, in his book *The Gene Illusion: Genetic Research in Psychiatry and Psychology Under the Microscope* (2004), suggests that “there are many environmental (non-genetic) factors shared by reared-apart and reared-together identical twins that would lead them to resemble each other more than two randomly selected members of the world’s population.”345 Joseph cites a number of instances that could lead to identical twins resembling each other besides genetic factors. For instance, identical twins are exactly the same age, ethnicity and sex; their appearance is strikingly similar; they are usually reared in the same culture, socioeconomic class and so on.346 These factors, he believes, could increase the behavioural resemblance of twins for non-genetic reasons.347 The main problem with Bouchard’s study, according to Joseph in *Twin Studies In Psychiatry And Psychology: Science Or Pseudoscience?* (2002) is that the investigators mistakenly compared reared-apart identical twin pairs (monozygotic twins) to reared-together identical pairs—failing to control for the fact that both sets share several important environmental similarities.348 If Joseph’s conclusion is correct, then behaviour resemblance to others may be influenced by such factors as age, ethnicity, sex, appearance, culture and socioeconomic class. This may reduce support for Velleman’s claims about the importance of family acquaintance for self-knowledge, if, for instance, we may be able to gain a better insight into what we will be ‘like’

---

343 Ibid.
344 Ibid.
346 Ibid.
347 Ibid.
by merely observing our culture and ethnic background rather than our genetic family members.

**In Defence Of Velleman’s View**

However, Joseph does not deny that genetics plays some part in what we will be like. Furthermore, people who are genetically related to one another are often similar in appearance, behaviour, and attitudes. Most of us recognise this about family members. Indeed, one adoptee (case 354), reporting to the New South Wales Law Reform Commission into open adoption raised this issue commenting, “We can see our real origins that identify our appearances, our attitudes, our characters, be they outgoing, reticent, sporting, entertaining, tall, short and as well our sexual preferences.”[^349]

In addition, according to research carried out by Jadva et al. for Cambridge University (2010), the number one reason donor-offspring wished to locate their half-brothers and half-sisters is curiosity about their appearance and personality.[^350] Therefore, it may be assumed that one of the main reasons donor-offspring search for siblings and half-siblings is to see what their brothers and sisters are like.

Furthermore, while it is recognised that social history would also impact a child’s identity, an actual account of their genetic family history forms an important part of their identity and it is that important part of their identity that I and Velleman think they ought to have access to, remembering that this is a good to which children raised by their genetic parents have as a matter of course from the family setup.

Since genetics plays some part in determining what we will be like (which seems to be the case in genetic medical conditions, for instance), then Velleman is quite right to claim that children who are being deprived of acquaintance with their genetic parents are at a disadvantage. However, while conceding that Velleman is right regarding the need for information about genetic parents, I am not calling for the more extreme knowledge of acquaintance that he supports.

**Conclusion**

Commissioning parents who do not inform their donor-conceived children of their donor-offspring status are depriving these children of important information that may impact not

[^349]: New South Wales Law Reform Commission, 2002(a), 5.81.
[^350]: Jadva, Vasanti et al., 2010, p. 528.
only their health and reproductive lives, but also their self-knowledge and identity formation. The reasons for withholding genetic family information from donor-conceived children in the past are no longer persuasive. Any advantages to commissioning parents gained through withholding the facts of their child’s birth from him would be only slight in contemporary Australian culture compared to the possible risks to their child of not having this information. Therefore, Velleman is correct to argue that it is unfair and immoral to deny donor-conceived children information about their genetic parents. Of course, by extension this argument applies to adoptees also. The possible impact on children’s self-knowledge and identity formation are further reasons for thinking that information about genetic parents is beneficial for children to have. It is because these children face the prospect of being disadvantaged by being without information about their genetic parents that they should be included among those who should be provided with access to information about their genetic parents.

Of course, it is not the case, that this information will not have a deep impact on some children and their families. There are some children, for instance, whose other interests may be more overriding. In the next chapter, I focus on the impact of my proposed policy shift on such families, if the information about genetic parents were to be made available for children to access.
7 Family Matters

In this chapter I look at more problematic cases than those addressed in adoption or donor-conception situations. If information were made available to children to access should they choose, information about certain genetic parents could impact family relationships, which could be jeopardised. For instance, when a child is born as a result of a concealed extramarital relationship in the context of a committed relationship, the disclosure of that child’s genetic parentage could greatly impact the social parent who did not know the facts of parentage and, as a consequence, the child. In the case where it is a male who learns that he is not the child’s father, news of this kind could lead him to leave the family, the child and potentially any other children in the family. Of course, disclosure in these cases would not be in children’s best interests.

On the other hand, as I have shown in the preceding chapters, non-disclosure of genetic parentage is not in a child’s best interest either. This is a dilemma, because if the child is informed of her genetic parentage, she may lose the opportunity to be reared in a family by two nurturing parents. However, if the child is not informed of her genetic parentage, she is at risk of, for instance, reduced autonomy in later life.

While I have argued that there are benefits to a child having the right contained in Article 7 of the CRC, there is an argument to be made that in certain situations withholding this right could result in greater benefits to the child. This is because this important right of the child could clash with her entitlement to be reared within a nurturing two-parent family. As a result, cases of misattributed paternity raise concerns that seem to be at odds with a child’s right to know her genetic parents.

In this chapter, I focus on the problem of a child’s right to information about her genetic parents in cases where her existence is the result of an extramarital affair in a committed relationship that, if revealed, would affect the status of her family life. These are cases where it may be considered more in the best interest of a child to withhold the information about her genetic parentage from her. Of course these are not the only types of cases that require greater consideration, rape and incest are cases that are just as problematic for disclosure of genetic parentage.

Explanations

While it is recognised that both men and women indulge in extramarital affairs that sometimes leads to the creation of a child who will be denied her right to information about
one of her genetic parents, for the purposes of this work, I only refer to instances where a child is born as a result of a mother’s extramarital affair. This is simply because it is easier to approach the problem from this perspective. However, my argument is intended to cover instances relating to the extramarital affairs of both genders that produce a child who will be denied her right to information about her genetic parents.

**Distinction Between Donor-Offspring, Adoptees, And Children Of Misattributed Paternity**

There is at least one distinction between donor-conceived children, adoptees and children of misattributed paternity that is relevant to my thesis when it comes to disclosure of genetic parentage. Most generally speaking, when donor-conceived children are deceived about their genetic parentage, it is by both their custodial parents, if they are in a two-parent household. That is, both parents of a donor-conceived child typically know of the child’s distinct genetic background but choose to withhold this information from the child. They may not know who the donor or donors are, but they know that a donor contributed gametes for the creation of their child. The case is similar for adopted children who are not told they are adopted. Again, most generally speaking, both adoptive parents partake in the deception of their adopted child. It is generally only the children (adoptees and donor-offspring) who are unaware that their genetic heritage is distinct from their social parents. It is, therefore, unlikely that in either of these two cases parental participation in family unity would be threatened if the child were informed that he was adopted or that he was donor-conceived.

However, this may not be the case for the child who is born as a result of an extramarital affair. In many of these cases, only one parent (the mother) knows the true genetic identity of the child. The husband may be living under the assumption that the child is his genetic offspring. Discovery of the facts of these children’s genetic heritages may result in the collapse of these family units because of interpersonal conflict between the parents.

As families of donor-offspring and families of adoptees are unlikely to break-up as a result of revelations about the child’s genetic parentage, I put these cases aside to concentrate on those cases where the family may break-up due to revelations about a child’s parentage. These are generally cases where a child results from an extramarital affair on the part of one partner in a committed relationship.

**Open Marriage**

Of course, not all families are in committed relationships that hold to the principles of monogamy. Some families are in open-type relationships, for instance. Sometimes referred to
as ‘open marriages’, both parties in these types of relationships, although committed to each other in all other respects, agree to allow their partners to take lovers outside of the marriage. Although somewhat distinct in its approach as a type of committed relationship, open marriage could lead to a child being born who is the offspring of one partner in the marriage and a lover outside of the marriage.

However, the candour that normally exists in open marriages makes it less likely that revelations of the identity of the outside genetic father of a child would lead the non-genetic father to break up the family unit. After all, in such relationships, both parties can and should recognise the risk of bearing a child to someone other than the relational partner. As open relationships are just that, open, it is most likely that the partners within the relationship would also be open to truth-telling were it known that the child’s genetic heritage was different from the social father’s. I, therefore, leave these cases aside also.

**Parentage Identity Unknown**

Of course, some mothers may not know the identity of the genetic fathers of their children. For instance, a woman may have an extramarital affair and be unaware that the resulting child is not the genetic child of her husband. While I acknowledge that a mother in such cases ought to have some doubts about who the father of her child is, I allow that it is entirely possible that she might not. In such a situation, both parents would be unaware that, in presuming they are both the genetic parents of the child, they were taking risks with the child’s welfare or breaching her right in Article 7.

On the other hand, it could just be the case that some genetic parents are simply negligent of their duty in regard to Article 7 of the CRC and their children’s rights to information about their genetic parents. Since my proposed paradigm shift would help identify the genetic parents of these children, in this section, I leave those cases aside, where revelation of the true identity of the genetic father would not cause any problems to focus on cases where this information would adversely affect family relationships.

**The CRC And The Issue Of Misattributed Paternity**

While the CRC makes it clear that adoptees and donor-offspring are entitled to the right to information on the identities of their genetic parents, it says nothing within its articles specifically about the rights of children to the identity of their father in, for instance, cases of misattributrition of paternity resulting from extramarital affairs. Nonetheless, it does seem to be a requirement of the CRC that all children are entitled to this right. Article 2 states:
States Parties shall respect and ensure the rights set forth in the present Convention to each child within their jurisdiction without discrimination of any kind, irrespective of the child's or his or her parent's or legal guardian's race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status.\textsuperscript{351}

I take the reference to ‘each child’ in this article to mean that \textit{all} children should be covered by the rights in this convention. Furthermore, by adding ‘without discrimination’, it is clear that the CRC intends to include all children, without exception.

As the CRC itself intends that all children be covered, I understand this to mean that this article also includes children of misattributed parentage. Article 7, therefore, would also entitle children of misattributed paternity to information about their genetic fathers, if it is known.

However, the CRC handbook does refer to arguments that were presented to the CRC concerning misattributed paternity. It holds that where there are concerns for the mother of extreme forms of “social condemnation, such as ostracism, injury or death” as a result of misattributed paternity, there should still be provision in place to release information to the child, “either with the mother’s permission or at a time when she will not suffer harm.”\textsuperscript{352} As extreme forms of social condemnation are not a likely event in Australia, given Australians liberal attitude regarding these matters, I leave this issue aside. Nevertheless, I do address the issue of women and children suffering abuse or worse if this information is exposed.

However, first, in relation to non-abusive households, we return to the following problem. Men who find out that they are not the genetic father of a child in their family may become angry at the mother, potentially leading to conflict and marital disruption (This may raise issues about a genetic and social father’s right to know, which are outside the scope of this work, as here I am concentrating on a child’s right to know). Therefore, in gaining access to information about her genetic father a child risks losing the stability of a two-parent household. This raises a conflict of interests for children. The question is whether the best interests of the child lie in being reared within a two-parent family unit or in having information about the identity of her genetic parents. It also raises the question of whether the child’s right to information about the identity of her genetic parents is as valuable a good as being reared in a two-parent family setting.

\textsuperscript{351} Department of Foreign Affairs and Trade, 1995, np.

\textsuperscript{352} Hodgkin, Rachel & Newell, Peter, 2007, p. 108.
The Case For The Family Unit

The importance of rearing children within a nurturing family setting is widely accepted. Indeed, Section 43 of the *Family Law Act 1975*, which lists what the Children’s Court should consider when making judgments, suggests the need to give the widest possible protection and assistance to the family, as the fundamental group unit of society. This indicates to me that the Children’s Court should place a high value on the family unit when making decisions regarding children.

The CRC also acknowledges the importance of the family in rearing children. The preamble to the convention states:

Convinced that the family, as the fundamental group of society and the natural environment for the growth and well-being of all its members and particularly children, should be afforded the necessary protection and assistance so that it can fully assume its responsibilities within the community.

The CRC states further, “that the child, for the full and harmonious development of her personality, should grow up in a family environment, in an atmosphere of happiness, love and understanding.” Indeed, it could be argued that the family unit, unlike any other, is a special relationship among persons with particular benefits for children, with great importance for the ‘full and harmonious development of their personalities’.

Furthermore, the family unit generally protects its members. Children are vulnerable, needing love and protection, and families generally do this better than other groups. Children need nurturing. Brennan and Noggle quite rightly argue that “the healthy mental, physical, and emotional development of children seems to require that someone have the responsibility to nurture and protect the child, and the authority to exercise her own judgment in doing so on a day-to-day basis.” Moreover, they argue, “Given that someone must do these things, and that children are often too immature to do so, it seems natural to assign parents the right to do so.” Being vulnerable, children need to be reared by someone until they attain maturity. It is usually best that this role be carried out by those who love them—typically their family, however constituted. For the most part, it is generally accepted that children fare better when reared within a family unit. Disrupting the family unit without good reason, therefore, would not be in the best interests of children.

---

355 Ibid.
357 Ibid.
Consequence Of Divorce For The Child

Furthermore, there are painful consequences to divorce. Indeed, were a family to divorce as a consequence of a child being provided with her right to the fulfilment of Article 7 of the CRC, this may have more adverse affects on the child than not providing her with the information about her genetic heritage. According to the sociologists Gay Kitson et al., in *Who Divorces and Why* (1985), for instance, “Given the high levels of distress reported in the decision period and the variety of problems that must be addressed in deciding to divorce, it seems likely that parenting would suffer during this period.”\(^{358}\) If parenting suffers, then it seems likely that children would suffer as a result. According to another group of sociologists, Paul Amato et al., “Experiencing parental divorce as a child may interfere with learning dyadic skills that facilitate successful marital relations, thus leading to a general increase in problems and an increased risk of divorce.”\(^{359}\)

If a child (and her social father) were informed of her genetic parentage, this may lead to her social father leaving the family home, the child and other children in the family. This means that a number of others, besides the child, would be impacted by this information. Therefore, the child, along with other children in the household, stands to lose a social father with whom she has bonded, along with his protection and psychological, emotional, financial and physical support. In addition, she may also experience animosity towards her from her social father, because she is a reminder to him of his wife’s extramarital affair, this is not to mention her siblings, who may also harbour resentment towards her because they may see her as being partly responsible for the family break-up. Clearly, providing information to the child about her genetic parentage in this type of situation is not in the best interest of the child.

Perhaps, in these instances parents should be permitted to withhold information that the child is the result of an extramarital affair. If the philosopher Shelly Kagan is correct that “so long as the child is not being harmed, parental rights are generally not to be infringed merely to provide some marginal benefit for the child”\(^{360}\), then this may be reason to withhold the right in Article 7 from some children. Given that a family break-up could harm the child as much if not more than some of the risks associated with non-disclosure, then perhaps it would

\(^{358}\) Kitson, Gay et al., 1985, p. 260.
\(^{359}\) Amato, Paul & Rogers, Stacy, 1997, p. 623.
be wrong to provide these children with the information, even though they may be entitled to it.

If disclosure of a child’s genetic parentage turns out to be detrimental to the continuance of the family as a unit, it may be prudent for a mother not to reveal this information to her family. Divorce can create detrimental situations for children. Depending on the circumstances, therefore, it may sometimes be better for the child to be denied her right to the fulfilment of Article 7 of the CRC in order to reap the benefits of being cared for within a two-parent family group. Indeed, it is highly plausible that in some households where infidelity has occurred resulting in misattributed paternity, the children have grown up healthy and loved and the parents go on to have a normal relationship.

**Arguments In Support Of Disclosure In Cases Of Deliberate Misattribution Of Paternity**

However, one reason for thinking that a child should still have information about her genetic parents, even in these cases, is that despite all attempts at concealment the truth may be exposed anyway. Others may know of the affair, or a social father may have doubts and may have the child DNA tested to allay his fears. Consequently, in these cases, not disclosing paternity may be only a short-term solution, and the family may eventually break-up anyway if the infidelity is exposed. So, even if a mother manages to hold her family together through deception, exposure of misattributed paternity will be an ongoing threat to the family relationship.

Furthermore, in some cases, the affair that led to the conception of the child may be a symptom of systematic problems and pathologies in the family that make it an unhealthy environment in which to rear children. If for instance, there were reasons the mother had an affair that was related to family disputes and a dysfunctional relationship, this would have an impact on the children reared in such a household. Children are not typically immune to the interactions between their parents. If these interactions are strained, this will impact children living in this environment. So, it could be more challenging for a child to be in a family where infidelity has occurred. Most generally speaking, if infidelity occurs in a relationship (assuming it is not an open marriage), then deception is probably involved. If deception surfaces in a relationship, trust in that relationship could be undermined. If a family is experiencing these sorts of problems, then it is most likely that children will feel the impact of that, which may also affect their wellbeing. As a consequence, children may not fare so well in these types of households. And if they are not doing well in such households, then there is no reason to think those family units are valuable for the children. Sometimes being
reared within a family unit consisting of a father and mother may not be beneficial for children in the long term. It is the case that many children are now being reared in single-parent households and appear to be managing quite well. Additionally, children are being adopted into single-parent and same-sex households. Therefore, the argument that in order to thrive, children need to be reared within a family that contains both a father and a mother is not as well-supported as it used to be. Single-parent households appear to do just as well as two-parent households when it comes to nurturing and caring for children.

**One Solution To This Dilemma**

However, if the family, as a unit with both parents, is the best environment for children to grow up in, then it would be good if the child of misattributed paternity, where the custodial father does not know this, could be given information about her genetic father without this impacting her family life to any great extent. As this issue raises a dilemma for the child’s best interest concept, information about genetic parentage could still be collected and made available to her when she attains 18 years of age and is fully independent. By the time a child attains 18 years of age, she has already been reared, and keeping the family together as a unit could be considered less essential for her growth and support. Although, adopting this policy would postpone fulfilment of the child’s right until she is no longer a child dependent on a nurturing family unit, it has the advantage of ensuring that the child is still reared and nurtured within a two-parent household while at the same time ensuring she gets the information to which she has a right under Article 7 of the CRC. This has the added benefit of only the child being informed, while still withhold the information from her custodial father. This may help prevent a family break-up.

**Problems With This Solution**

However, there are problems with adopting this policy. First, it would deny the child her right for an extended period of time. Second, it might also be considered temporarily dishonest. Third, there is a possibility that some children may suffer genealogical bewilderment as a result of finding this information out later in life. The fourth reason is that when this information is withheld until this late in a child’s life, there is the possibility of him unknowingly having sexual relations with a sibling or half-sibling. The fifth reason is that he risks suffering an unexpected genetic health problem that might be worsened by the lack of accurate genetic family health information. The sixth reason is that a lack of this information could see his autonomy reduce for an extended period of time. The seventh reason is that his
narrative identity would have been impacted in this period of time. This situation is clearly
not ideal and ignoring these risks is not in the best interest of the child.

In addition, postponing fulfilment of an adoptees right could have an impact on her
younger siblings, if she has any. For instance, if the adoptee is not informed until she is 18
years old and she has younger siblings who do not know, finding out when their sister turns
18 years old may also have an impact on them. Thus leaving the disclosure of this important
information until the adoptee is older may also be a risk for her siblings, if they are not
brought up to know the truth about their sister. Of course, this is not a problem if the child
has no siblings or her siblings are older than her. However, where she has younger siblings,
withholding information about her genetic parents from her until she is older has the added
risk of impacting others in the family besides the child of misattributed paternity. Of course,
if the child is told at an early age and her siblings are also brought up knowing this fact, then
this would help avoid problems for her siblings also.

Discussion

There is clearly a problem with informing children of misattributed paternity who their
genetic fathers are when their social fathers are unaware that it is not them. A father in such a
situation may leave his family, denying his children the benefits of his protection and support.
To resolve this problem, information about genetic parents could be withheld from children
of misattributed paternity until they attain 18 year of age. While there are some risks attached
to delaying these children their right to information until that time, these risks are outweighed
by the benefits to their being reared in two-parent families, with all the advantages attached to
that and without risking family break-ups during children’s formative years. In addition, if a
child is given this information on attaining 18 years of age, these risks would be reduced.

Accepting that children have a prima facie right to information about their genetic
parents and that they are also entitled to be reared within a nurturing two-parent family raises
a dilemma that can only be addressed through the above compromise, or through a paradigm
shift capable of handling these challenging cases. Withholding information about genetic
parents from children of misattributed paternity until they reach 18 years has the advantage
that, if a child is being reared in a two-parent family (where revelations of this sort could
cause a family break-up), withholding this information may prevent a family break-up. This
creates the possibility of the child being reared within that family unit until she attains
adulthood. This is certainly in keeping with the CRC directive to make the information
available to a child of misattributed paternity ‘at a time when she will not suffer harm’.


**Problem Cases Of Rape**

What about children who have been conceived as a result of rape? Should children who are the product of rape be told of the circumstances of their conception or be given the identity of their genetic father? Perhaps the raped mother would suffer further if this information were made available to her child. Perhaps, this information could harm the child psychologically (stigmatisation, feelings of repulsion and so on). Such harms to mother and child may outweigh any benefits the child could derive from having information about her genetic father.

Rape provides a special case in which, in my view the information about their genetic father should never be provided to children or only with the consent of their mothers. Thus, instances of rape could be one exception to the rule of providing children with any information about their father. Rape is an exceptional case that requires us to weigh the interest of the child to information about her genetic father against the possibility that having this information may bring her into contact with a criminal, who has shown himself capable of a violent crime against her mother. Due to the possibility of further harms to the mother and the possibility of harms to her child, in these situations, it may be best for all concerned if such persons were not identified to the child as their genetic father, unless the mother agrees to this information being provided to her child. So, unlike children of misattributed paternity, who may have to wait until they attain 18 years of age, children born as a result of rape should not have this information provided to them unless their mother consents to them having it.

In line with these cases are those of children who it may be thought should not be told because the discovery of who their genetic father was, for instance, may be too distressing for a child to deal with. One could imagine the news that one’s genetic father is Adolf Hitler, for instance, or some other despicable character, could cause shock and alarm impacting a child in a serious way. One could only imagine the impact this would have on one’s narrative identity, for instance. A child might be led to wonder if they had their genetic father’s nature, in the case of Hitler, for example. This might lead to the child suffering psychological problems. Again, these are difficult cases and it is understandable that one would not want to provide such information to children about their genetic heritage in these cases. Although, it is true that these children’s health, autonomy and reproductive choices would be compromised by withholding this information over a long period of time, when weighed against the impact that telling them they are genetically related to a mass murderer could
have on their sense of self, it is thought better to wait until the child is older and better able to deal with this information.

**Problem Cases Of Incest**

It could also be argued that information about the identity of a genetic father should be withheld from children conceived as a result of incest also due to the repulsion they may feel or the stigmatisation they may suffer should this information become known to others. It could be argued, for instance, that withholding information about these children’s genetic fathers would not involve denying them genetic family information (including genetic family health information), since they would know their father, for instance, as a grandparent or uncle and so on. Therefore, they would not be expected to suffer unforeseen health risks due of a lack of genetic information. Of course, these children may suffer genetic problems because of the close genetic ties between their father and mother, but this is not the basis of my thesis. However, in essence they would have available to them (at least as much as most other members of the general public have) the information called for in Article 7 of the CRC—all, that is, except the knowledge of their true relationship to their genetic father. Of course, this could be made available to them on reaching 18 years of age, in line with children of deliberate misattributed paternity.

Incest, when it is exposed, is usually given media coverage. It would be unlikely, therefore, that children born as a result of incest would not be aware of that. However, if the information about their genetic father was managed to be concealed from them, then this could be another exception to the rule of children having information about their genetic parents.

**Problem Cases Of Abusive Relationships**

Another problem arises where disclosure of the genetic parentage of a child could cause a mother and child to be abused or murdered. The danger of a jealous spouse abusing or, worse, killing his wife and child, is small but real. There were approximately 77 intimate-partner homicides in Australia between the years 1989 and 2002.361 The majority of these involve males killing female partners,362 some were as a result of jealousy.363 According to Martin Daly et al., psychologists who have done extensive work in the field of interpersonal

---

362 Ibid., p. 1.
363 Ibid., p. 3.
conflict and violence in families, “Male sexual jealousy is a leading motive in homicide and other acts of violence.”  

Peter Chimbos, a sociologist who has written well-known work on intra-family violence, found in his studies that “Male sexual jealousy and ‘proprietaryness’ are the predominant motives in the killings of wives by husbands.”  

Clearly, some men could not be informed that a child they thought was their genetic offspring was not. If a father was considered abusive or a threat to a mother and child because of disclosure of misattributed paternity, then it would be wiser for a mother not to disclose this information. It would not be in a child’s best interest to have information collected or disclosed that could possibly lead to her being abused or her life endangered or her mother being abused and her life endangered.

It may be assumed that abuse would be a more physically and mentally harmful prospect for a child than revelations that the man she believes to be her father is not. Therefore, it would be wrong to insist, in cases where a social father is abusive or dangerous that a child ought to be provided with information about the identity of her genetic father. However, in line with the handbook (as mentioned earlier in the chapter), this information could be withheld from the child until such time as the threat to her and other family members is gone.

While withholding information from the child until later in life may lead to problems of genealogical bewilderment, as previously stated, this is not a chronic condition. Therefore, there is a good chance a child will get over this psychological problem given enough time, especially if she is made aware of the reason why the information was withheld from her. However, while such a father is a threat, this may means that a child, who along with her mother is in danger of abuse and harms, may never be informed. In such cases, it could be argued that genealogical bewilderment is a better prospect than having no life at all or one where the child or mother is in constant fear and danger of abuse or worse. However, while I accept that there are exceptional cases, ultimately I hold that knowing the identity of one’s genetic parents is beneficial, even if they are not likeable people.

**Conclusion**

The family is the best environment, most generally speaking, in which to rear children. As a result, it may be in the best interest of some children to delay providing them with this information if disclosing it could result in their family breaking up while they are still young.

---

364 Daly, Martin et al., 1982, p. 12.
and vulnerable. Of course, withholding this information from a child until she attains 18 years of age involves some risk to her health and psychological welfare. However, that may be a better option than denying altogether her right to genetic parentage information as specified under Article 7 of the CRC.

However, we may also have to make allowance for exceptions of providing information about genetic parents to some children, for instance, in cases of rape, incest and where there are risks of abuse and murder, in the best interest of the child and her mother. Instances where the child or her mother could be harmed through revelations of misattribution of paternity pose particularly difficult cases in terms of the best interest of the child and her right to information about her genetic parents. In some of these cases, it may be best to defer to the mother's decision regarding providing information or not. Other cases include where the information would be too shocking to provide to a child because the information would be too alarming. Thus the above cases of rape, incest (where the child does not know this) and cases of misattributed paternity (where there is the possibility of harm to the child or her mother) provide special cases whereby children should, perhaps, never be informed of their genetic parentage. This is considered to be in their best interests and to avoid harms to them and other family members.

Leaving these types of cases aside, in the next chapter, I discuss ways that children can know the identity of their genetic parents, even in cases where the social and genetic parents refuse to provide them with this information.
8 The Benefits Of Mandatory DNA Testing Of Newborns

As previously discussed, children can have rights under the Interest Theory account of rights. The CRC has been ratified by Australia, placing an obligation on the government to ensure that the rights in this treaty are fulfilled. The CRC includes the right in Article 7 for children to know about their genetic parents. I have also argued that children would benefit from having access to this information and, indeed, they may be harmed without it. However, even under the current paradigm of openness in adoption and donor-conception, it is still the case that some children may never learn this important information about themselves. While it may be impossible to rectify this state of affairs for today’s children, there is a way to solve this problem for future generations. For instance, under a paradigm of DNA testing of all newborn babies and their alleged genetic parents, it would be possible to identify those parents with genetic links to their children. DNA testing for genetic parentage is currently commercially available and it is one option worth considering for a number of reasons, which I present here. In this chapter, I propose such a system of DNA testing newborn children and their presumed genetic parents. Of course, for this method to be fully effective, it would need to be instituted as mandatory, perhaps with penalties for non-compliant parents. For, it is my view that without making DNA testing for parentage mandatory, children may continue to be denied access to their right as expressed in Article 7 of the CRC.

DNA testing is not such an unrealistic suggestion. Indeed, a few countries have instituted it. I begin this chapter by discussing those countries that currently have mandatory DNA testing to identify genetic relationships between parents and children and those who forbid DNA testing for parentage identification. In addition, I discuss the benefits of a lead-in period prior to instituting DNA testing for parentage in order to prepare people should my paradigm shift ever be implemented into law. I also discuss the benefits of adopting this means of identifying parentage rather than some others.

China’s DNA Database

China has introduced DNA parentage testing of some Chinese citizens in order to unite stolen children with their genetic parents. Stolen and missing children are a major problem for China where recent figures from an online report by Kay Bratt suggest that as many as 20,000 women and children are abducted each year in China. In order to combat this

366 Bratt, Kay, 16/05/2011, np.
problem, according to a news report by Cao Li, “A nationwide DNA databank has been launched to help authorities identify abducted children and return them to their families.”  

A 2009 news report states that “Blood samples will be taken of all parents who report missing children and it will be stored on the databank, allowing scientists to test their DNA against any youngsters police rescue from abduction, find homeless or begging in the street, or suspected of being kidnapped.” So, China has set up a database specifically to identify genetic relationship between parents and their children. China uses DNA testing to establish parentage because it has proven so effective in identifying stolen children. Of course, this method of establishing genetic parents is used only for specific cases, such as abducted children; not all children are DNA tested. However, where it has been used, the indications of success at establishing genetic parentage of children are good. For instance, in 2000, DNA testing proved successful in reuniting 546 abducted and missing Chinese children with their parents. This indicates that, despite China’s only recent use of DNA testing to identify stolen children, DNA testing is an effective tool in identifying genetic relationships and reuniting children with their genetic families. Clearly DNA testing for parentage is advantageous in identifying genetic parentage when those parents want to be identified. The Chinese government’s use of DNA testing shows that this policy can be instituted as a means of solving certain identification problems.

Of course, by only testing some children, other children are ignored—particularly those children whose parents do not declare them missing, for instance. By not DNA testing all children, China could be accused of treating ‘abandoned’ children whose parents do not report them missing differently from stolen children, whose parents do. Ensuring that all children were treated equally would require the Chinese government to include the DNA profiles of every citizen in its database to identify the genetic parents of all stolen and ‘abandoned’ children.

If the Chinese DNA database is an indication of the ability of DNA testing to identify individual genetic relationships, then clearly a number of current problems regarding genetic identification of individuals in Australia could be solved with the institution of DNA testing of children, not only as a means of avoiding marginalising some children, but also in order to

---

367 Li, Cao, 01/05/2009, np.
368 Ibid.
369 Ibid.
370 Ibid.
ensure that all children have the same advantages when it comes to the benefits of identifying their genetic parents.

Indeed, a number of countries collect DNA samples from their citizens, most generally in instances related to criminal cases. However, rather than give an account of each of them here, I have supplied a table in Appendix 1 consisting of 14 European countries and five G8 countries that collect DNA samples from their citizens, including an account of the number of DNA samples contained in each of their databanks. However, before I move away from those countries that use DNA testing as a means of identification of their citizens, I want to raise the issue of Argentina, who has also introduced mandatory DNA testing to identify genetic parents of children.

**Argentina’s DNA Parentage Testing**

Argentina introduced mandatory DNA testing of some of its citizens, again as with China, to identify the genetic parents of stolen and adopted children, according to one news report by Mayra Pertossi.371 Like China, Argentina also has a problem with stolen children, in this case children who were stolen and adopted illegally by members of the military or police during the 1970s dictatorship.372 According to the same news report by Pertossi, “Valuing truth over the right to privacy, Argentina’s Congress has authorized the forced extraction of DNA from people who may have been born to political prisoners slain a quarter-century ago—even when they don’t want to know their birth parents.”373 Pertossi explains, “Human rights activists hope the new law will help find about 400 people stolen as babies, many from women who were kidnapped and gave birth inside clandestine torture centers during the 1976–1983 dictatorship.”374 It is understandable that families whose children were stolen under these circumstances would be anxious to find out what happened to their children—whether they were still alive or not, for instance. The use of DNA testing to identify these stolen children would prove a very useful tool. Pertossi reports, “DNA technology has helped the Argentine government identify 98 of 500 children born in prison or kidnapped as babies.”375 Again, we note the ability of DNA testing to solve the problem of stolen children.

However, while impressive in its ability to identify the genetic parents of children, DNA testing has also proved problematic for those stolen children, the very people, one would

---

372 Ibid.
373 Ibid.
374 Ibid.
375 Ibid.
imagine, it was intended to help. The main issue with DNA testing in the case of Argentinean stolen children is that some of those stolen children do not want to know if they were stolen nor who their genetic parents are, if they were. This has not deterred the Argentinean government, however, in their bid to identify stolen children. Although human rights activists may have been hoping that this way of identifying genetic parentage of a child is in the child’s best interest, this has not always proved to be the case. For instance, in Argentina if a person refuses to provide a sample of DNA for testing, a judge can issue a warrant for genetic material from a hairbrush, toothbrush, clothing or other objects.\textsuperscript{376} An example of this occurred in 2001 when Evelyn Vazquez refused to submit to a blood test, hoping to prevent DNA results from being used against her adoptive father, a former Navy officer who was facing charges of child theft of his daughter during the military dictatorship.\textsuperscript{377} At the time the Supreme Court upheld her decision.\textsuperscript{378} However, in 2008, a federal judge ordered a search of her personal effects, and DNA from her toothbrush and underwear finally proved that her genetic parents were armed Montoneros militants killed in 1977.\textsuperscript{379} Clearly, Argentinean courts can enforce DNA testing of personal items, even if the adoptees do not want to know who their genetic parents are. Of course, this response on the part of Argentinean adoptees may be understandable if DNA testing leads to the conviction for criminal offences of her adoptive parents. Clearly, this was a problem for Evelyn Vazquez. Despite the human rights hopes of doing what is in the best interest of the child, in these types of cases, it is hard to see how this outcome would be in the best interest of the adopted person, especially if the truth leads to a gaol sentence for her social parents. Of course, these Argentinean stolen persons are no longer children when the information is presented to them. Although unwanted by them, the information that their social parents are not their genetic parents and, indeed, are most likely responsible for the torture and deaths of their genetic parents is not being presented to them in childhood when this information could greatly impact them.

\textbf{One Problem With Argentina’s Mandatory DNA Testing Of Children}

As a result of the harsh circumstances under which Argentinean adoptees are presented with information about their genetic parents, some may have concerns about the mandatory nature

\textsuperscript{376} Ibid.
\textsuperscript{377} Ibid.
\textsuperscript{378} Ibid.
\textsuperscript{379} Ibid.
of the DNA testing methods employed by the Argentinean government to identify stolen children’s genetic parents. For instance, the new law could be accused of permitting unacceptable government intrusion into people’s lives. In addition, forcing adult adoptees to comply with mandatory DNA testing may raise concerns because it can remove the adoptee’s choice of whether or not they want to have information about their genetic parents. Had Evelyn complied with the law without making it a court matter, perhaps she could have requested not to know the results of the tests. However, while this solution may have worked in other situations, it could not work in this situation because the Argentinean government are looking for parents of stolen or kidnapped children, leading to the arrest of those parents. As these are criminal cases, there may be little chance, when such ‘adoptive’ parents are discovered, to avoid the media exposure that is going to naturally ensue. If these ‘adoptive’ parents are guilty of the crime of kidnapping or stealing children, it is most likely that there will be legal proceedings and that the matter will become public knowledge, as it did for Evelyn Vazquez with the result that she would find out the result whether she wanted to know or not. Of course, I am not advocating that children or adults, for that matter, should be presented with information that they do not wish to have, since I fully support their right not to have this information, if that is their choice. Neither do I approve of unnecessary intrusion by governments into people’s lives. However, clearly these are exceptional circumstances involving potential criminal cases being investigated by the Argentinean government and so, what happens for stolen children in Argentina is not what would be expected to happen under normal circumstances.

Nonetheless, despite its shortcomings, Argentina is testimony to the fact that DNA testing can be made mandatory with courts enforcing the removal of DNA samples for testing. While Argentina and China clearly support the idea of identifying genetic parents of certain children, not all countries support DNA testing for genetic parentage; one such country is Germany.

**Germany’s DNA Testing**

Like most counties now, DNA testing for parentage is commercially available in Australia and parents can establish the genetic parentage of a child for themselves. However, Germany, has instituted new laws aimed at preventing the misuse of genetic DNA parentage tests. One of the targets of the legislation is secret DNA testing for paternity. As the law now stands in
Germany, with the exception of abuse and rape cases, paternity testing requires consent from both alleged genetic parents. Furthermore, according to an article by MacKenna Roberts for BioNews, “Offenders who conduct paternity tests without the consent of the other parent face a fine of 5,000 euros under the new law.” As a result, DNA testing is outlawed in Germany in cases of fathers trying to determine paternity of a child without the mother’s consent. The law also holds the same for women, in that a mother cannot get a DNA test to determine the father of her child without the consent of her partner. Of course, this does not mean that the German government is against DNA testing per se, just that it is now illegal to get tests done on a child without both her parents’ consent. Indeed, this may be a stipulation by the German government because both parents being DNA tested is necessary to obtain an indisputable result. A child’s DNA consists of 50% from each parent. Although by testing one parent we can isolate their DNA from that of the child—that is, what is left should then belong to the other parent—it is preferable to test both parents to obtain an exact result. Thus there may be advantages to preventing parents from DNA testing their child without the consent of both parents, such as there is not the same accuracy when testing only one parent as there is when testing both. This is important when it comes to the proposal I suggest; for in order to ensure the accuracy of the result, that is, to ensure the results are 100% accurate, we need to DNA test both genetic parents. I do not support a policy that is anything less.

**Problem With The German View On DNA Parentage Testing**

However, this could be problematic for the mother, for instance, if the father refuses to consent and the mother wants to do the right thing by her child and establish genetic paternity. She may want to do this in order to fulfil the child’s right as expressed in Article 7 of the CRC, for instance. The same would hold, if a father wanted to dispute paternity and the mother refused the test. This could be interpreted not as a win for either genetic parent, but rather as a loss for both as neither can realise their desire to fulfil their rights to know what children they have genetically created. Furthermore, they cannot help their child to realise their right as stipulated in Article 7 of the CRC.

---

380 Ibid.
381 Ibid.
382 Roberts, MacKenna, 26/05/2009, np.
383 Ibid.
384 Medvet Laboratories, nd, np.
With the introduction of this law, Germany prevents parents from finding out who fathered a child, for instance, by preventing either parent from testing the child without the consent of the other. Some could interpret this as an infringement of parents’ rights to know who their genetically related children are. Thus there are some concerns with Germany’s efforts to prevent parents from establishing their genetic relationship to their children. Of course, by denying parents, their right to identify their genetic connectedness to their children, they, by extension, prevent children from gaining access to the same information—the information that is called for to be provided to children in Article 7 of the CRC. As a result of these concerns there has been some opposition to the new German laws concerning DNA testing. For instance, in opposition to the new laws, the German Medical Association has argued that the new laws “may be too restrictive and lead to medical tourism by individuals travelling abroad seeking the desired genetic testing potentially in places without adequate provision and quality standards.”

Since there is nothing to prevent parents going abroad to have their DNA tests carried out, the law merely prevents parents getting their testing done in Germany. As the main concern with testing abroad appears to be that the provisions provided for the test may be inadequate and the quality standards may be poor, the conclusion that may be reached is that the result may not provide an accurate account. This would be problematic if the result was unexpected and false. Clearly, DNA testing should provide an accurate result on this important issue.

**Secret Paternity Testing Is Problematic**

Germany aside, Australian citizens also find secret paternity testing problematic. In their paper *DNA Paternity Testing: Public Perceptions and the Influence of Gender*, Turney et al. (2003) carried out a survey on DNA testing that included a number of groups composed of both men and women, including men and women who had been involved with DNA paternity testing. This survey indicated that respondents were comfortable with the idea of DNA testing only where all parties provided consent.

Presently in Australia both parent’s consent is not required, but, like the German government, some believe that it is better to have both parents’ consent at the time of testing and to test both parents together because of the heightened accuracy of testing with DNA.

---

386 Ibid.
387 Turney, Lyn et al., 2003, p. 27.
samples from both parents. The survey by Lyn Turney et al., seems to indicate that the Australian public’s only real concern with DNA parentage testing is to make sure that both parents consent to the testing of their child.

Despite this preference for the consent of both parents when carrying out DNA testing of a child to identify genetic parentage, however, a number of testing clinics in Australia carry out paternity testing without the mother’s consent. Ian Smith from Genetic Technologies states, that this situation is currently under regulatory review, but a ban on testing in Australia without the mother’s consent has yet to be introduced. Clinics may be carrying out secret DNA testing because they believe that fathers should have an equal right with mothers to know this information. Preventing fathers from finding out this information in Australia will not prevent them from sending their samples overseas to be tested, as was highlighted by the German Medical Association in relation to the German ban on secret testing.

Mandatory DNA parentage testing has other real benefits for future children. Aside from the benefits to wellbeing, autonomy identity and so on, it would help to ensure that future children are not secretly DNA tested. Mandatory DNA parentage testing would reduce or eliminate fathers getting their children secretly DNA tested, since the child would be tested at birth and the genetic parents identified at that time. Thus DNA testing could solve all disputed paternity cases and finalise them early in the lives of children, making life more stable for children in the long term. Mandatory DNA parentage testing would eliminate the impact that secret paternity testing may have on children, especially when the results prove to be unexpected or false.

Taking on board the issues relating to Germany’s concerns about one parent testing, under my proposed paradigm change, both parents would be required to provide DNA for testing where possible. This would not only eliminate the need for secret tests by either parent, but would also ensure that the test for parentage was as accurate as possible, thereby eliminating the potential problems faced by the German government regarding secret and inaccurate DNA parentage testing.

**Suspicion About Paternity**

In addition, it is reasonable to think that as a flow on effect of mandatory DNA testing, disputes about genetic parentage would be a thing of the past. Generally, fathers seek secret

---

388 Ibid.
389 Roberts, MacKenna, 26/05/2009, np.
DNA testing because they are suspicious about their genetic connection to a child. Following discovery of a non-genetic connection to a child, a father who has been supporting that child will seek to relinquish not only their psychological and physical support, but also their financial support for that child. According to psychologists Martin Daly and Margo Wilson in their book *Homicide,*

Mammalian fathers who are about to make paternal contributions confront a problem that mothers are spared, a problem so serious that it largely explains why most mammalian fathers opt out of paternal investment altogether. That problem is the uncertainty of paternity.390

‘Mammalian’ (*adj*), according to the Collins English Dictionary, refers to “any animal of the *Mammalia,* a large class of warm-blooded vertebrates having mammary glands in the female, a thoracic diaphragm, and a four-chambered heart. The class includes the whales, carnivores, rodents, bats, primates, etc.”391 Given humans are classified in the order of *Primates,* I take Daly and Wilson’s quote to also refers to human fathers. If fathers are suspicious about paternity and secretly DNA testing their children and, on discovering that they are not genetically related to their children, are withdrawing their support from those children, this would surely impact those children in a negative way.

**Refunding Child Support To Non-Genetic Fathers**

As a consequence of the costs of child support on some genetic parents, some suspicious fathers now secretly DNA test their children in order to ascertain their child support obligations and to recover any monies mistakenly paid under the impression that they had fathered these children. According to the ethicist Mary Anderlik in *Disestablishment Suits: Daddy No More?* some ‘duped’ fathers are fighting the payments, not because they wish to discontinue support for the children, but “rather, they want to end the legal obligation to pay child support that might flow to the women who deceived them in two ways: by cheating on them and by lying to them about a child’s paternity.”392

These days, law courts in Australia increasingly rely on the use of DNA testing to positively identify genetic fathers in order to establish their liability for child support. The absence of a genetic link between father and child is used to relieve fathers of their financial obligations and responsibilities and in some instances money is refunded when it was paid in good faith for children these men mistakenly believed they fathered. For instance, following a

---

390 Daly, Martin & Wilson, Margo, 1988, p. 180.
landmark case in 2006, Australian policy changed to release the men who are not genetic fathers of their children from any commitment to pay child support and to have what was paid because of deceit refunded.\textsuperscript{393} The move to cease holding non-genetic fathers liable for child support in Australia was first witnessed in the \textit{Magill vs. Magill} case in 2006.\textsuperscript{394} In this case a father (Liam Magill) had carried out secret DNA testing on his children following the break-up of his marriage only to discover he had been misled about the paternity of two of his children.\textsuperscript{395} He filed a tort of deceit of paternity and although the tort could not be applied in this case, Magill was released from his child support obligations based on the DNA findings.\textsuperscript{396} One can only imagine the impact this had on his children when they were given the information in this way, especially as it was played out in the media, only to have that followed by the loss of Magill’s financial support.

In addition, “The new law, Section 143 of the \textit{Child Support (Assessment) Act}, which came into effect on 1st January 2007, requires the Family Court to consider issuing orders for repayment whenever paternity is successfully challenged.”\textsuperscript{397} Once DNA paternity testing establishes non-paternity, the next step seems to be court proceedings by the non-genetic father to recover child support payments that were paid for non-genetic offspring. This can amount to a debt recovery from the mother of sums in excess of $70,000 in some cases, depending on the number of children and the length of time the man has paid child support.

Following the Magill case, Ken Rodgers went to court to reclaim his child support payments after he paid $200 a week over 10 years for a child that was not his genetic offspring.\textsuperscript{398} According to a news article by Kelvin Bissett, in 2007, Rodgers obtained a court order to recover $60,000 of the $71,000 he paid to the child’s mother over the years he thought he was the child’s father.\textsuperscript{399} Rodgers’ success appears to have led to many more such court cases. For instance, according to the same report by Bissett, in 2008 a further 344 men obtained court orders cancelling their child support obligations for children who are not genetically their offspring.\textsuperscript{400} Supporting a child that you have been deceived into believing is genetically yours can seem very unfair to some. Many think that this new policy is a fairer system for men and children.

\textsuperscript{393} Australasian Legal Information Institute, nd, Sect 143(1) (b).
\textsuperscript{395} Ibid., p. 2.
\textsuperscript{396} Ibid.
\textsuperscript{397} Australian Legal Information Institute, 2011(a), np.
\textsuperscript{398} Ibid., 9/11/2010, p. 2.
\textsuperscript{399} Ibid., 11/11/2008, np.
\textsuperscript{400} Ibid.
As stated in the introduction, the American Association of Blood Banks’ (AABB) records show that as many as 30% of children tested by men suspected of fatherhood are not the genetic children of those men.\footnote{American Association of Blood Banks, 2006, p. 4.} If the figures from the AABB are accurate and these figures also equate with Australian society, then this may be also lead to an increase in the number of cases of children being secretly DNA tested by alleged fathers suspicious about their genetic links to their children. This, no doubt, would be followed by an increase in the number of appeals before the courts for exemption of child support payments from those proved to be non-genetic fathers. This debt recovery process of child support through the courts could have an adverse impact on some children’s lives as they may have to face a reduced standard of living, once financial support is withdrawn and the recovery debt introduced.

However, the advantage of my policy shift for children and parents following mandatory DNA testing is that the identities of the genetic parents would be known following the birth of the child and, therefore, these sorts of court proceedings would no longer be necessary. Following mandatory DNA testing of all newborn children, the identities of their genetic parents would be established as fact and the whole issue of genetic relationships between parents and children would be resolved once and for all for those parents whose children are tested; future fathers would no longer be in doubt or, for that matter, be able to deny their genetic connections to their children.

Benefits to children would include no longer having to undergo secret DNA tests to establish or disestablish genetic links to their fathers. Additionally, children’s links to their genetic father would be identified without contest in a court of law, as is currently happening. Thus there would be no suspicious genetic parents or children for that matter following mandatory DNA testing for genetic parentage. Of course, the children who were born before the introduction of mandatory DNA testing would still be at risk of secret DNA testing by their parents, but my policy cannot account for those children’s right to information.

Mandatory DNA testing for genetic parentage would also resolve the problem that people in general have with secret DNA testing without both parents consent for the accuracy of results. The paradigm shift to mandatory DNA testing of newborns and their genetic parents, therefore, has the advantage of eliminating cases of suspicious fathers DNA testing their children without the mothers’ consent, since both genetic parents would be tested at the same time—providing the most accurate result. These are outcomes that would arise naturally
following the testing of both genetic parents. Therefore, mandatory DNA testing of newborns would help solve some of the problems surrounding the current practice of fathers carrying out covert paternity tests to identify whether or not they have genetic connections to their alleged children prior to taking the matter to court for child-support recovery.

My proposed policy shift, therefore, has the advantage of being able to overcome some of the past problems associated with covert DNA paternity testing of children. In addition, and most importantly, my proposal would satisfy the requirements necessary for children to realise the fulfilment of their right as expressed in Article 7 of the CRC.

**Lead-In Period To Provide People With Enough Time To Prepare**

Despite the benefits of using DNA testing to identify genetic parents of children, it would be wrong to introduce mandatory DNA testing straight away with little or no notification to the public, given that it could cause alarm for some people if the results for parentage were unexpected. In addition, given that there may be problems if mandatory DNA testing of newborns and their presumed genetic parents was to be introduced, it would be improper to make this a retrospective law; that is, such a law would need to be implemented only for children born after its introduction. As we have seen with adoptions, there are problems with making policies retrospective for some people.

Furthermore, it would be unfair to deprive mothers and fathers or prospective mothers and fathers of an opportunity to prepare for mandatory DNA testing of their children. One way to avoid this problem is to provide at least two years notification of the introduction of a mandatory parentage testing law. This would provide people with sufficient time to adjust to and prepare for the new paradigm shift. Providing people with ample time to prepare for this mandatory process would help future parents to adjust to their duties of fulfilling their children’s right as expressed in Article 7 of the CRC.

Through clandestine DNA testing there is a potential to expose cases of misattributed paternity, thereby publicly exposing problems in family relationships. Mandatory DNA testing, were it introduced with a lead-in period of a number of years, could prevent these sorts of problems from occurring. With the introduction of mandatory DNA testing, clandestine testing would be unnecessary, since the results of the test would be conclusive. This is an advantage on clandestine testing, which may not be as accurate if both parents are not tested with the child at the same time.

Furthermore, providing enough notice to parents that DNA testing was going to be instituted, allows them to prepare for the birth of their child with the full knowledge that they
would have to comply with a mandatory DNA testing procedure following the birth of their baby. Of course, this would not be enough. Parents would also need to be aware who was going to be tested, by whom and how. I address each of these issues in turn, starting with who should do the testing.

**Who Should Do The Testing**

If instituted into law, mandatory DNA testing of newborns and their alleged genetic parents would require that the tests be carried out by a government-approved specialist at the hospital or clinic where the child is born. This would be for the convenience of the parents and their children. This would mean they did not have to go somewhere separate to the hospital or clinic to have the tests done. The database containing the information should also be maintained by a government agency or government regulated agency rather than an unregulated private enterprise. This is for data protection reasons (I return to the discussion of privacy issues and data protection of the proposed DNA database in the following chapter) and in order to regulate and monitor the database on a regular basis. DNA samples for testing should be taken by trained nurses in the hospital or clinic where the child is born in order to ensure the samples are not contaminated in any way and the tests are as accurately applied and controlled as possible. Homebirths may require the genetic parents to attend a hospital or clinic with their child for testing so that the child’s profile can be added to the database.

**Who Would Need To Be Tested To Identify Parentage Of Newborn Children**

Of course, to identify the genetic parents of children it is not necessary to DNA test all Australian citizens, since not all citizens will be parents of children. While it may be more egalitarian to DNA test everyone to avoid marginalising or discriminating against some citizens, for the purposes required here, it is only necessary to DNA test genetic parents and their children. So, in light of the concerns addressed earlier, mandatory DNA testing of newborn children and their alleged genetic parents should include the following:

- Mandatory DNA testing of all children and any adults suspected of being a child’s genetic parents, until matches are found;
- Maintaining the information in a secure manner;
- Informing the child at an appropriate age of the identities of the two matched persons; and
- Where there are no genetically matched parents to the child, keeping the child’s DNA information on record in case of future matches.
DNA parentage testing requires that a buccal swab (or other biological material) be taken from the child and each presumed genetic parent. If the process is conducted at the birth of the child, the child’s umbilical cord could be used to extract a sample of DNA from the baby for testing.\textsuperscript{402} This avoids invasive procedures being carried out on newborn children.

Furthermore, if DNA parentage testing became mandatory for all children at birth, it would need to be carried out on a number of people, with the resulting profiles maintained in a database for future disclosure to children. I suggest the following people should be considered for testing following the birth of each child:

1. the child,
2. the alleged genetic mother,
3. the surrogate mother, if relevant,
4. the legal father,
5. the alleged genetic father, if different from the legal father.

In the case of \textbf{group 1}, each newborn child or children (in the case of multiple births) would need to be tested, since recent studies show that, “If a woman has sexual intercourse with at least two men during a polyovulatory period, superfecundation could result and the twins could have different fathers.”\textsuperscript{403} This means that in the event that a woman produces a number of eggs in a cycle, each of those eggs can be fertilized by different men, resulting in multiple births where each child has a different genetic father. Consequently, each father and the children would need to be DNA tested in order to obtain an accurate result.

In the case of \textbf{group 2}, I use the term ‘alleged’ here to indicate that prior to testing we are unsure exactly who the genetic mother is. In most cases, the woman who gives birth to the child is the genetic mother. However, there can be cases in which this is not so, for example, in cases of surrogate pregnancy. So, in this event, the birth mother would need to be tested to ensure that she is the genetic mother.

In the case of \textbf{group 3}, should the birth mother turn out to be a surrogate mother, then the alleged genetic mother will also need to be tested, along with the surrogate birth mother. The surrogate birth mother may need to be tested to eliminate her as the genetic mother. This would not need to be carried out if the genetic mother is identified in advance.

\textsuperscript{402} Genelex Corporation, 2010, np.
\textsuperscript{403} Girela, Eloy et al., 1997, p. 1159.
If the genetic mother is unknown, as in the case of egg donors, the child should still be tested to allow for a possible match with the mother at a later date. If there are a number of possible candidates for genetic motherhood, then all candidates should be tested until a match is found. If there are no candidates for testing, then the child’s DNA profile ought to be left open and stored in the database in case a match to her genetic parents can be made at a future time. Maintaining an open profile of children who cannot be matched to their genetic parents allows for the possibility of future connections if the genetic parents ever come forward in the future for testing.

Of course, it is still possible that some children will not be able to obtain information about their genetic parents—overseas adoptees from China, for instance. Indeed, it may not even be possible to establish genetic parentage for some Australian children. For example, a woman may have had a number of sexual partners, not all of whom can be located at the time of the birth of the child. Furthermore, it may not be possible to gain this information in cases where a child is ‘abandoned’ and the woman and the child’s father never come forward for testing. For these reasons, it is best to test as close to the birth of the child as possible, because the longer after the birth the testing takes place; the harder it may be to locate her genetic parents.

In the case of group 4, I use the term ‘legal’ to indicate that prior to testing we are unsure exactly who the genetic father is. If the mother is legally married or has a partner she indicates is the genetic father of the child, he should be tested. If the mother indicates it is another man, then we go to group 5 on the list.

In the event of group 5, if the mother’s partner is not the genetic father of the child and this has been established though DNA testing or the mother can establish that someone else is the genetic father, then the genetic father of the child should be tested, presuming he can be located.

If the genetic mother does not know who the genetic father is or where he is, then the child and the mother should be tested just the same and the results held in the DNA database until such time as the genetic father can be located and tested. Again, if there are a number of possible candidates for fatherhood, all candidates should be tested until a match for the child’s genetic father can be found.

Should the mother genuinely not know who the father is, or when there is no way to establish genetic paternity, we may want to consider leaving these profiles open in such a way as to allow future links to be made when the genetic fathers come forward.
In cases where the results of DNA testing call genetic parentage of the legal parents into question, a number of people may be required to submit to testing to establish genetic parentage. However, given that some children’s DNA profiles may need to be left open for future connections, it may be unnecessary to test numerous alleged parents of a child at the time the child is born. A DNA database could eventually identify all genetic parents, after a certain period, who were not available for testing at the time of the birth. In fairness to people, they should be notified of this possibility, if my policy shift is ever considered for institution into law that contains this provision. In this way, parents would be aware that the possibility existed that a genetic match could be made at some point in the future to the genetic parentage of each child born after a certain date.

**Penalties For Refusing To Submit To Mandatory Testing**

However, we should consider the possibility of some parents refusing to submit to DNA testing. This would be problematic for the identification process and mandatory DNA testing would not be successful as a tool to help children realise their right to information about their genetic parents, if parents could refuse to submit to testing. Therefore, some penalty would have to be considered in the event that some parents refused.

Giving people plenty of notice of the institution of DNA testing to identify genetic parentage would provide them with time to come to terms with the type of information that is required for the test, such as the identity of the genetic father, for instance. Since, of course, parents would have to comply with DNA testing if it ever became mandatory and the data collection of information about genetic parents was to be successful, where parents refused to be tested, the government would have to consider imposing some sort of penalty in order to ensure that parents complied with the law. While it may be considered that alleged genetic parents should have a right to refuse to be DNA tested for proven genetic parentage, here I draw on the harm principle presented by the philosopher John Sturt Mill in *On Liberty*, which states, “The only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant.”404 As previously stated, children are at risk of harms if they do not have information about their genetic parents. In order to prevent these harms, it would be permissible, under Mill’s harm principle, to exercise power over alleged

404 Mill, John, Sturt, 1861, p. 10.
genetic parents in order to ensure they complied with mandated DNA testing for genetic parentage.

On the other hand, if we consider that Mill is wrong about having the right to exercise power over others when they are a potential harm to others, this surely cannot be the case, since we do exercise power over others when they pose a potential risk to others by preventing them from doing so through incarceration, as is the case with murderers and psychopaths. So, there appears to me to be some justification for taking Mill’s harm principle as sufficient grounds for exercising power over alleged genetic parents when they are requested to provide DNA samples for testing.

Of course, where there are the potential risks of harm to a child or her mother, for instance, as previously stated, as a result of providing this information to children, Mill’s harm principle, I presume, would have to weigh in on preventing the greater harms, which I assume here to be the harms brought about by abusive and lethal husbands, rape and incest cases. These possible exceptions to my proposed paradigm shift should be among those considered as justifiable reasons for refusing to be DNA tested. Individuals should be able to apply to the government for an exception to avoid being penalised for non-compliance in these particular cases.

However, leaving these exceptional cases aside, where there are no justifying reasons other than some slight benefits to genetic parents, I have considered a number of penalties that could be used where alleged genetic parents refused to comply with the law regarding DNA testing. Imprisonment, for instance, is one option, that was considered. The possibility of imprisonment may work as an incentive to comply with a mandatory law. After all, who would wish to undergo imprisonment rather than provide a DNA sample for testing? However, imprisonment seems a harsh penalty to impose on an alleged genetic parent who refused to comply with DNA testing. If for instance, a genetic mother refused to divulge the identity of the genetic father of her child, would we consider her removal from her family (including the child whose right we are trying to protect) justifiable? This type of penalty would not only affect the genetic mother; her family would also suffer as a result—the loss of her nurturing while she was in prison, for instance. There is also the stigma of having a mother branded as a criminal and all that that entails.

Furthermore, despite its harshness, this type of penalty does not offer any certainty that a genetic mother will comply and provide the necessary information. It may be more important to her to protect the identity of the genetic father of her child. Thus imprisonment may be too
harsh a penalty for refusing to comply with mandatory DNA testing for children, genetic mothers and their families.

On the other hand, a genetic father may refuse to come forward for testing, if he does not want to recognise the child as his genetic offspring. In such a situation, should his penalty be any harsher than the genetic mother who does not want to identify him? These are important questions that would need to be considered if imprisonment were considered as a penalty for not complying with mandatory DNA testing. Of course, imprisonment is not the only option.

Another less imposing penalty I considered was a term of community service. This penalty is sometimes considered a fair punishment for breaking certain laws. Genetic mothers and fathers, who refused to comply with DNA testing, could be sent out to contribute to the community in some way. As a penalty, this is less harsh than imprisonment with its loss of the genetic mother and her care, for instance. Furthermore, it would only require the mother’s/father’s absence from the family for minimal periods of time during the day. Children would not suffer as badly as they would if their mother, for instance, was imprisoned.

However, it was considered that while this may produce a better community, it would be a minimal deterrent for some genetic mothers and fathers who considered community service less than a strong force for truth telling or submitting to DNA testing. Furthermore, it was thought that very young children may still suffer the loss of their mother while she is away performing community service, even if it was for only short periods of time each day. Again, it seems to me that it would be better to install a system or penalty that did not adversely affect any children and that could be applied equally to both genetic parents.

Another option I considered as a penalty for alleged genetic parents who refused DNA testing was to withhold government payments from those genetic parents receiving government benefits. It is well known, for instance, that money sometimes works as an incentive to get people to comply with certain rules. Government benefits could cease when alleged genetic parents do not comply with the rules surrounding mandatory DNA testing. Withholding government payments may provide more of an incentive to genetic parents to comply with mandatory DNA testing than the prospect of community service.

However, again, this may be a harsh penalty, especially for those families dependent on government support. Furthermore, the children in those households would suffer the loss of the family’s income support. In addition, this penalty could not be applied to those alleged genetic parents not receiving government benefits. So, another penalty would need to be considered for those alleged genetic parents. This option is, therefore, problematic because it
may lead to problems of marginalisation for those on government benefits and it could also lead to a number of penalties having to be instituted for different types of households. These are major disadvantages to instituting this sort of penalty.

Another penalty that was considered, which is similar to the previous penalty, is the institution of fines. Fines could be applied to all alleged genetic parents who refused to provide DNA for testing whether they receive government benefits or not. While it may be argued that fines would also impact the children of those alleged genetic parents, this would surely be dependent on the extent of the fines. For instance, the amount of the fine could be worked out by the government using some formula for different household incomes following discussion into the impact of fines on different family types and so on. Government, of course, would need to ensure that fines did work as a deterrent. For instance, if the fines were too low, then they would most likely not work as a deterrent and, if they were too high, the household children of the alleged genetic parents could suffer the resulting demand on the family finances. Remembering that we are trying to do what is in the best interest of the child, it would be wrong to badly impact one child’s life in a family in an effort to improve another child’s life in the same family or to impoverish one child’s life in an attempt to improve another’s.

Another problem with instituting fines as a solution to alleged genetic parents refusal to be DNA tested is that imposing a steep penalty may actually result in a number of persons being named as the alleged genetic father of a child. This may be done by a mother for instance, in an attempt to show willingness on her part to comply with the law, if she does not know the identity of her child’s genetic father. She would do this obviously to avoid any penalties for refusing. This could result in a long drawn out procedure as each alleged genetic father is located and DNA tested only to be eliminated, while yet another possible candidate is located and DNA tested. This could go on ad infinitum.

Certainly, the government need not institute penalties at all, since the alleged genetic parent’s compliance could simply be overridden. For instance, the government could do what the Argentinean government do and take DNA samples from other items belonging to the alleged genetic parents, such as combs, clothing and toothbrushes, for instance. This would be one way to ensure that the DNA samples are obtained when alleged genetic parents refuse to comply with mandatory testing laws. However, this solution could only be applied where the alleged genetic parents are known; it would not be helpful where the genetic mother, for instance, refused to divulge the identity of the genetic father or she does not know who the genetic father of her child is.
Of course, instead of penalties for refusing to submit to DNA testing, people could be rewarded for complying with the law. For instance, a monetary value award could be presented to each alleged genetic parent who provides their DNA for testing. Of course, the value of the award would have to be substantial enough to encourage those alleged genetic parents who were opposed to DNA testing to comply. The problem with this solution is that it is unlikely to encourage those alleged genetic parents who are not swayed by money to provide their DNA for testing and it would be costly for the government to provide a financial reward that was substantial enough to persuade them, if there is a monetary amount that could.

Clearly, there are problems with each of these considered penalties and rewards. Nonetheless, they show that penalties or rewards could be instituted to encourage genetic parents to comply with DNA testing should it become mandatory. Of course, there may be other and more appropriate ways to address this issue. If there are, then it would be more appropriate to consider those.

Despite the problems that may arise when seeking to ensure that genetic parents comply with mandatory DNA testing, there are many advantages to adopting this method of identification rather than any other available options that can be used to identify genetic parents, the most notable being that DNA testing is a popular means of identifying genetic parentage.

**DNA Testing Is A Popular Means Of Identifying Genetic Parentage**

Of course, people can currently get their children DNA tested for genetic parentage themselves through a number of clinics that provide this service commercially. Indeed, most of us hear stories about paternity DNA testing when celebrity cases make the headlines, such as the much-publicised claims to the singer James Brown’s estate by a number of his alleged children following his death. However, it is not only celebrities’ children who are resorting to DNA testing to prove or disprove paternity; many fathers and mothers also use this service to identify genetic connectedness to their children.

Moreover, it appears that the instances of DNA paternity testing are on the increase. According to Mark Bellis, Director of the Centre for Public Health at Liverpool John Moores University in the UK, in *Measuring Paternal Discrepancy and Its Public Health* (2005) “Between 1991 and 2001, the number of people seeking paternity tests more than doubled in
the U.S. to 310,490.”\textsuperscript{405} In addition, according to the ethicist Mary Majumder, Associate Profession of Medicine and Medical Ethics at the Center for Medical Ethics and Health Policy at Baylor College of Medicine in the US and Mark Rothstein, founding Director of the Institute for Bioethics Health Policy and Law at the University of Louisville School of Medicine in the US, in \textit{DNA-Based Identity Testing and the Future of the Family: A Research Agenda} “in 1998, the states spent $31,511,137 on laboratory testing for paternity.”\textsuperscript{406} Although these figures relate specifically to America, DNA paternity testing also seems to be on the rise in Australia, according to a report by Rachel Carbonell for ABC radio’s PM program.\textsuperscript{407} In that report, Ian Smith, Director of Service Testing at Genetic Technologies—the first private company in Australia to use DNA technology to carry out paternity testing—states that the most common use of DNA testing is, “where someone has been named as the father of the child, and a person or an organisation is seeking maintenance payments from that person.”\textsuperscript{408} It is likely, under the current paradigm that the numbers of Australians getting paternity tested compare proportionately to US figures. Clearly, as a means of identifying genetic connectedness, DNA testing is very popular with people and governments alike.

However, this increase in DNA paternity testing has the potential to adversely impact some families, such as in cases where no genetic connection between fathers and their children are found, leading to the possibility that some men will leave their families on discovering this fact. Currently, clandestine testing for paternity is causing concern, because it is most often carried out by an alleged father without the mother’s consent. As we noted, this was one of the issues raised by the German government. Should a man find out he is not the father of a child, he may inform the child of this and, if he is angry enough, he may sever all bonds between them. No doubt this would be very painful for the child, if their bonds have been forged over many years of her life, for example. If a father chose to leave his family because of a discrepancy over genetic paternity, this could lead to trauma in his child’s life. This would hardly be in her best interest. This would be particularly unfair for all concerned, if the results were misleading or false because they were not obtained from a reputable laboratory or were obtained without both genetic parents DNA samples. As both parents would be tested together with the child by a government regulated agency with trained staff.

\textsuperscript{405} Bellis, Mark et al., 2005, p. 752.  
\textsuperscript{406} Majumder, Mary & Rothstein, Mark, 2002, p. 218.  
\textsuperscript{407} Carbonell, Rachel, 23/03/2005, np.  
\textsuperscript{408} Ibid.
under my policy shift, the results would be reliable. As a result, mandatory DNA testing of newborns and their alleged genetic parents would eliminate the need for secret tests and could potentially avoid the problem of fathers leaving their families, due to genetic paternity discrepancies following secret testing. Thereby avoiding the problem faced by Germany of having to mandate against secret testing, which raised concerns about the accuracy of the results of clandestine tests.

My proposed paradigm shift would establish genetic paternity at the birth of the child, thus ensuring that the child is not going to be left unsupported because of a lack of a genetic connection to her social father. If a social father is going to leave his family because of a lack of genetic connectedness to a child, it would be better if this were done at the beginning of the child’s life, before strong bonds were formed between them. Finding out the genetic connectedness to their children when those children are born prevents later claims in the courts for returns of child support, since there could be no reclaiming back child support money on the grounds that it was obtained through deceptive means. Thus children would not be disadvantaged through the loss of this financial support being reclaimed from mothers by deceived fathers. Of course, since people would be aware that their children were going to be DNA tested when they are born, should my proposal ever be introduced, it is unlikely that there would be unexpected genetic parentage results. One would imagine that these issues would be sorted out between genetic parents prior to the birth of their child. This is the purpose of my proposing a lead-in period of at least two years prior to introducing mandatory DNA testing for genetic parentage.

Of course, whether my proposal is introduced or not, DNA testing is proving to be a very popular means among the general public of identifying genetic connections between individuals. It is a particularly popular means of identifying the genetic parents of children. Aside from it popularity with the general public, DNA testing is also a reliable means of identifying genetic connections between individuals.

**DNA Testing For Genetic Parentage Is Reliable**

Previously, we did not have the technology to tell us with complete accuracy who was genetically related to whom. In the past, there was never any doubt about the mother; she was always the one who gave birth to the child, so her identity was indisputable. At the same time, the identity of the genetic father was heavily dependent on whether or not he was married to the mother at the time of her pregnancy. The belief was that, “If a husband, not physically incapable, was within the four seas of England during the period of gestation, the
courts would not listen to evidence casting doubt on his paternity”.409 In other words, so long as a man was married to a woman, any child born into the family was considered genetically related to him whether the child actually was or not.

Of course, this old English method of identifying parentage is no longer suitable. One reason for this is the number of persons who can be involved in the birth of a child these days: the surrogate mother, gamete donors and so on. These people, generally speaking, do not wish to care for a child themselves, but are happy to provide the means for others to do so. However, until the introduction of Artificial Reproductive Technology and DNA testing, if there was doubt about the paternity of a child, for instance, we could test her blood group (ABO, rhesus, Kell, Duffy, etc)410 to identify the genetic father. This test was not very reliable, however, given that many people share the same blood group, but it would have been a lot more reliable than the husband’s presence within the four seas of England.

“In the 1970s a more powerful test was developed using white blood cell antigens or Human Leukocyte Antigens (HLA), resulting in a test that was able to exclude about 95% of falsely accused fathers. Several millilitres of blood are required to perform the test.”411 While this test was more reliable than previous methods of determining paternity, it was less than adequate compared to modern DNA tests because it still left a margin of doubt. This is one of the reasons that we no longer rely on this method of identifying genetic parentage.

DNA testing has a number of advantages over other alternative ways of identifying genetic parentage. The most obvious advantage to using DNA testing to establish genetic parentage of children is that it is the most reliable method we currently have at our disposal. As I stated in the introduction, DNA testing is rated 99.99% accurate in determining paternity and is 100% accurate in determining non-paternity. It is equally accurate at identifying maternity. Its reliability is one of the main reasons that so many countries rely on DNA testing as a means of identifying certain individuals and family connections. As a result of its noted reliability, DNA testing is now the most commonly used method to determine connectedness and non-connectedness between parents and their children.

Indeed, DNA testing for genetic relationships is so reliable that its results are accepted in courts of law and by government departments. As it is such a reliable means of determining genetic relationships, several countries have endorsed DNA testing as a viable means of

---

410 GeneSys Biotech, ny, np.
411 Findlaw, 2011, np.
solving some of their most puzzling problems, such as crime, medical conditions, and genetic parentage.

However, the accuracy of DNA parentage testing must be assured, because of the emotional impact the result can have on some parents. To this end, the National Association of Test Authorities (NATA), Australia's Government-endorsed provider of accreditation for laboratories and similar testing facilities, put out a statement in 2005 recommending that “Parentage testing, given the huge emotional impact on all involved, must be transparent, traceable and above all undertaken with the utmost confidence in the outcome.” For completely accurate information, therefore, DNA testing needs to be carried out by a reputable facility under strict government conditions and guidelines. This could be achieved by a government run agency or a government endorsed agency, using qualified staff for instance. Only a system that is reliable ought to be considered as a means of identifying genetic connectedness. Anything that provides less than complete accuracy ought not to be considered because of the problems inaccurate results could cause families, and especially the children we are trying to protect. It is because of its accuracy in identifying genetic connectedness that I recommend DNA testing as the best means of identifying children’s genetic parents so that children can realise their right as expressed in Article 7 of the CRC.

**DNA Testing For Genetic Parentage Is Safe And Easy**

In addition to being popular and reliable, DNA testing is safe; that is, there are no harmful side effects from performing this procedure. Although biological samples are usually taken by mouth swabs to identify genetic parentage, biological samples from other parts of the body can be used as well. Tests can be conducted using hair, finger nails, skin, semen or teeth and from objects with bodily fluids on them, such as cigarette butts or toothbrushes. These were some of the items considered by Argentina when seeking to DNA test Evelyn Vazquez, as previously discussed. The ability of DNA testing to be carried out on items aside from the person, makes DNA testing a quicker, painless and less invasive method of identifying genetic connectedness to parents than testing by blood group, which requires an actual blood sample be extracted from the person, considered a painful procedure by some. Given the alternatives, DNA testing is simple, easy and painless. Furthermore, if DNA parentage testing were to include DNA from the baby’s umbilical cord, this would make it a completely non-invasive procedure for children.

---

Procedures Are In Place

Some may be surprised to learn that mandatory DNA parentage testing already exists for some people in Australia. The Australian Government, for instance, enforces DNA testing in cases where fathers dispute paternity in order to avoid child-support obligations. The sociologist Michael Gilding highlights this fact in his paper *DNA Paternity Testing Without The Knowledge Or Consent Of The Mother*. Gilding notes:

> Since its invention, DNA paternity testing has become an industry in its own right. It has been institutionalised through family law and associated institutions—in Australia, the Family Court, Legal Aid and the Child Support Scheme. Mothers are now required to enforce the tests in order to secure child support from reluctant fathers who deny paternity and do not wish to pay child support.\(^{413}\)

Of course, it is in the government’s best interest to identify genetic parents in child support cases in order to reduce the burden on government finances.

Furthermore, there are many websites advertising DNA testing, which shows that this service is already widely available in Australia. The number of approved clinics operating with services for genetic parentage testing, the use by government agencies of this service and the reliability of the tests all suggest that the procedures are already in place in Australia to carry out DNA testing to government approved standards, should the government decide to make DNA testing mandatory at the birth of a child. With so much reliance on and acceptance of DNA testing as an accurate means of determining genetic parentage and non-parentage, and with the procedures in place to implement and execute this program, it is my view that the government can implement the use of this tool to identify genetic parentage. As the procedures to reliably test are already available, DNA testing is considered here a viable means of identifying genetic parents of Australian newborn children in order to facilitate fulfilment of the child’s right as expressed in Article 7 of the CRC.

DNA Testing For Genetic Parentage Is Cost Effective

However, some may argue that the cost of DNA testing all newborn children and their alleged genetic parents is not a viable option, given the many demands on the government budget. This thesis is looking at what is primarily a moral based issue regarding children’s rights, rather than a financial one concerned with government spending. Therefore, one response to the problem of costs might be that children have a right under the terms of the CRC to know the identities of their genetic parents and, therefore, we ought not to even

\(^{413}\) Gilding, Michael, 2004, p. 68.
consider costs when it comes to something as important as rights. After all, we would find it
difficult to consider abandoning our right to life or freedom of thought and expression just
because there were costs involved. Therefore, why should we surrender our right under
Article 7 of the CRC simply because there are costs involved?

However, from a utilitarian perspective or simply from a practical perspective, there may
be a conflict of interests involving opportunity costs. Therefore, the costs of any new social
policy do matter. As a result, while I primarily focus my argument on promoting the best
interest of the child, I take a brief look in this section at the costs to government of making
my proposed policy shift mandatory. It is fully recognised that setting up, collecting samples,
analysing tests and storing and maintaining a DNA database of information would place an
additional strain on government resources. This may be reason enough for thinking that we
ought not to consider such an undertaking, given that there are already many demands on
government resources.

However, I argue that DNA testing is a cost-effective means of identifying genetic
parentage. It currently costs approximately $310 to test a child and both parents in a
commercial clinic.\textsuperscript{414} Of course, companies that offer the service for this price do so while
still making a profit, or else they would not be working in this field. A government-run or
government endorsed operation not intending to make a profit from this service could reduce
these costs significantly. In addition, we may expect these costs to decline as newer
technologies come to the fore. While costs of DNA testing have declined over the years and
no doubt will continue to fall as science and technologies improve in this area, costs will
nonetheless be an important concern if the government ever decides to undertake mandatory
DNA testing of newborns and their parents. Of course, if scientists produce a more cost
effective way to determine genetic parentage, that is also just as reliable as DNA testing, then
we should consider using that method instead of DNA testing, since we should always seek to
incorporate the best available options. However, even while we wait for scientists to advance
technology that would help reduce the costs of DNA testing; this is still a cost effective way
to solve the problems associated with determining genetic parentage. This view is not only
based on the cost of a family getting DNA tested at a private clinic as just stated, but it is also
based on the costs of running a government DNA database that has already been set up to
collect DNA information on citizens.

\textsuperscript{414} Nimble Diagnostics Australia, 2011, np.
The Expense Of Running The UK Criminal Database

In my view, the best indicator of what it would cost to run a DNA parentage database is to look at a database that has already been set up and that is currently running at a cost to a government. The UK criminal database (NDNAD) offers just such an example. According to a report by James Slack for the *Daily Mail*, the National DNA Database (NDNAD), set up in Britain in 1995, is the largest in the world per capita.\(^{415}\) It is also growing by 30,000 samples each month.\(^{416}\) Indeed, NDNAD is increasing its DNA profile count at a rate of one person a minute according to a Panorama report.\(^{417}\) It is said to currently contain in excess of 5.5 million people’s DNA.\(^{418}\) Despite this enormous amount of samples contained in its database, according to a BBC News report in 2007, it costs approximately £4.50 to store each sample for the first 5 years.\(^{419}\) This would be approximately AU$7.85\(^{420}\) at a rate of exchange in 2011. It is recognised that costs will have increased somewhat since 2007, but these prices give some idea of the costs of storing DNA profiles in a database over a number of years. However, while it may cost as little as $7 to $10 for each child’s profile to be stored, this does not include the cost of testing.

According to the Nuffield Council on Bioethics in 2007, it would cost approximately £700 million to record the entire UK population.\(^{421}\) During the same period, according to a news report by Evan Davis, the UK population was approximately 61 million people.\(^{422}\) It should be noted that this is only to record the profiles of the population, it does not include the $7 to $10 costs per person of storing and maintaining the database. However, if embarked upon, recording the DNA of their entire population would amount to a very expensive undertaking (at £700 million) for the UK government. Nonetheless, the UK government seems to be attempting to absorb these costs in an effort to reduce crime statistics and to include the entire population of DNA profiles in the NDNAD.

Of course, one would expect that if Australia were to establish a similar DNA database to contain parentage information, there would also be the initial costs of setting up the database. This cost would also need to be factored in when considering the overall costs to the Australian government. Given all these costs that would need to come out of the government

---

\(^{415}\) Ibid.
\(^{416}\) Ibid.
\(^{418}\) Pugh, Gary, 2009, p. 10.
\(^{419}\) BBC News, 18/09/2007, np.
\(^{420}\) Ostermiller, Stephen, 2011, np.
\(^{421}\) BBC News, 18/09/2007, np.
\(^{422}\) Davis, Evan, 23/10/2007, np.
budget, DNA testing would need to be fully justified in order to make it a worthwhile proposition for the government to undertake.

**Australian Database Not Nearly As Costly As UK**

Of course, Australia is significantly different in some ways to the UK. For instance, Australia currently only has a population of approximately 22 million, roughly one-third that of the UK. It could be estimated, therefore, that it may cost as little as £252 million, or AU$404, million to record the entire Australian population based on the costs of the UK NDNA in 2007, using current Australian population figures and the current rate of exchange (2011).423

Although costs are relative and these figures are only an estimate, what counts is that they provide a rough indication of the costs involved of such an undertaking.

In addition, it is not necessary to record the entire Australian population in order to identify the genetic parents of newborn children. We need only DNA test parents and newborn babies as each child is born. Therefore, the initial costs would be much less than the $404 million required to DNA test the whole population. With only 295,700 births in Australia in 2009424 (the latest available figures in 2011) the cost of DNA testing each of those children and their genetic parents would roughly amount to $5,500,000 to government. Allowing for inflation and the increase in costs since 2007 (the year the calculations are based on), if birth rates stayed steady, then it could cost the Australian government less than $10 million yearly to meet its obligation to fulfil the right as specified in Article 7 of the CRC.

Of course, the creation of a DNA database would incur initial set-up costs, but this would be a one-off cost. However, maintenance of the database would create ongoing costs for governments. The current cost of maintaining the UK database, for instance, gives a good indication of what such a database would cost the Australian government. The smaller size of the Australian population compared to the UK, however, means that an Australian DNA database would not be nearly as expensive to run and maintain as the UK one. Based on the figures from the UK, the costs of maintaining the profiles in a database, even at a cost of $10 per record, would only amount to an additional $2,957,000 per year to the Australian government. Although this may still seem costly to some, as previously stated, it is expected that these costs would decrease as newer technologies become available.

---

Some Ways To Recoup Costs

Furthermore, there are a couple of ways the government could recoup these costs. One would be to establish a fee for each certificate containing the information about the genetic parents, as is currently the case with birth certificates. Of course, instituting such a cost may not recoup enough revenue to cover the expense of collecting, storing and maintaining a DNA database with this information, but it would help.

However, if the certificate were too costly to produce, this extra cost could place great stress on the parents’ finances, for instance. In order to help those who could not afford to pay for a certificate if it were too expensive, the government could implement a means test to help decide how much of the cost should be placed on the recipients. As with healthcare schemes and, say, housing, it is not unreasonable to think that those that can afford it should cover a substantial amount of the costs of this service being instituted for their benefit. Naturally, those who choose not to know would not be expected to pay for information they do not want, as is the case for birth certificates.

Another method to help cover the costs of DNA testing newborns and their genetic parents is to institute a new lottery. People in Australia like to partake in lottery draws in the hope of striking it rich. This option has benefits for the genetic parent, their children and the general public who buy the tickets. It would help reduce the cost of the certificate, bringing it down to an affordable cost. This would benefit parents and children who want the information but cannot afford to pay for it. The buyers of the lottery tickets would have a chance at winning the top prize or another prize more valuable than the cost of the ticket.

Furthermore, people have the choice with a lottery ticket of whether to support the rights of children or not by buying or not buying one. A lottery draw may be a better option for people than government raising taxes to cover the costs of DNA testing, where some members of the public may baulk at having to pay for the fulfilment of children’s rights. This may be especially so when they do not have any children themselves or they think children’s rights are not important enough to warrant increased taxes. Of course, increasing taxes is another option available to government. The problem with instituting additional taxes is that once a tax is instituted, people are not provided with a choice about paying it. This is one benefit that a lottery has over an increase of taxes as an option for recovering the costs of DNA testing; people have a choice about buying a ticket in it.

Of course, this is not to say that an increase in taxes of a dollar or two per citizen would not be able to meet some or all of the costs of DNA testing new born children and their
alleged genetic parents, but rather that I think this option will not be as favourably received by the general public as a lottery would. Of course, it is recognised that there are other ways that the costs of DNA testing of genetic parents and their children could be recouped, besides those mentioned above. What I seek to show here is that just because there is a cost to government of instituting mandatory DNA testing, there are at least a few potential ways that these costs could be recovered.

**Expense Of Mandatory DNA Testing Can Be Justified**

The introduction of talk about costs seems out of place in terms of honouring our agreements. Nevertheless, there are reasons to think that the burden of costs to citizens of introducing my proposed paradigm shift bears some consideration. The following reasons are grounds for thinking that government should support the costs of DNA testing for parentage:

- Children have a right to know who their genetic parents are under the terms of the UN Convention on the Rights of the Child. Children can have rights on the Interest Theory account of rights.

- Australia would be honouring its ratification of this convention. According to the philosopher, John Rawls, “when we enter an agreement we must be able to honor it even should the worst possibilities prove to be the case. Otherwise we have not acted in good faith.”

- Besides the fact that children generally want to have information about their genetic parents, there are benefits to children having this information, such as healthcare, incest avoidance, reproductive reasons, identity and self-knowledge reasons, reduced autonomy reasons and reasons of holding to the truth rather than fancy. Thus, we have good reason to support the costs of a DNA parentage database because it would better provide for children’s futures.

- Other countries already use DNA testing to identify genetic parents of children.

- DNA is a popular means of identifying genetic connection. It is also a reliable means of doing this. It is also safe and easy and need not be intrusive and the procedures are already in place to carry out this measure.

---

- It eliminates the need for one parent to carry out clandestine testing in order to recover child support paid following deception about genetic connections to a child.
- Although, the burden of costs in establishing a database and collecting DNA profiles for storage may seem heavy, there is reason to believe that costs are not unreasonably high and could be recouped by charging for the parentage identification certificate, or by a number of other ways, including a lottery.

The number of benefits gained by children in setting up such a system, it seems to me, outweighs the costs of undertaking such an enterprise.

Clearly, there are a number of good practical reasons for thinking that the costs of DNA testing newborn children and their genetic parents, as a means of seeking to ensure that the information required by Article 7 of the CRC is available for children to access should they so choose, are justified.

**Additional Benefits For Future Children**

Despite some concerns, mandatory DNA testing has real benefits for future generations. For instance, in one hundred years from now, if testing began today, it would be unnecessary to test the parents of all children born in Australia, since all parents’ DNA, who were born in Australia, would already be held in the DNA database. This would mean that only newborn children would have to be DNA tested. As the years of DNA testing increased, fewer parents would need to be tested. Of course, immigrant parents and their children’s DNA would also have to be included in the database to have a full account of all genetic relationships between all Australian citizens.

This issue aside, the benefits of introducing DNA testing in the future, therefore, would include having to test fewer people as the years go by and having in place a reliable system that would allow for future children to gain information about their genetic parents that under the current paradigm is unavailable to them. However, more importantly, the new paradigm I am proposing would ensure that children’s rights to know of their genetic parents were honoured and protected rights.

Unfortunately, however, DNA testing of newborns and their alleged genetic parents cannot guarantee that genealogical information will be available for all future persons, since there may be cases where there is no access to parental DNA, as, for instance, when parents are dead or missing. Furthermore, it cannot help those children who already exist. However, despite these problems, my proposed shift to mandatory DNA testing of newborns and their
alleged genetic parents has many benefits over the current paradigm. One of the main benefits for children is that this would lead to fulfillment of the right specified in Article 7 of the CRC, which I have shown can be achieved through mandatory DNA testing of newborns and their alleged genetic parents. Indeed, mandatory DNA testing may be the only means of addressing this issue.

**One Solution For Dealing With The Problem Cases**

One way to deal with problem cases is to provide a special application form for genetic mothers to use that ensures that they alone are presented with the DNA results. These genetic mothers could, if the results were to prove detrimental, present an alternative version to their abusive partners. While I do not support lying under normal circumstances, these are exceptional cases where mothers and children are in danger, as previously discussed. This ensures that the correct information is still recorded, while protecting the child and her genetic mother while they are in abusive relationships from potentially greater harms than those incurred if children do not know the identities of their genetic fathers.

**Conclusion**

The introduction of mandatory DNA testing of newborns and their alleged genetic parents to address the problem of children’s access to information about their genetic parents may seem controversial. However, DNA parentage testing is being carried out by a number of countries. There are many advantages to DNA testing over other types of methods used to identity genetic connections. Furthermore, it is the most reliable method of detecting genetic relationships that is currently available. DNA testing is universally used as a means of identifying genetic parentage, which is testament to its reliability and people’s trust in its results. In addition, DNA testing is cost effective and could be more so if the service were conducted by a not-for-profit agency, such as a government run agency. The methods to institute DNA testing as a practical option in genetic parentage detection are already in place. DNA testing is a viable option and I believe the only viable solution currently available to address the problem of children being denied their rights to the fulfillment of Article 7 of the CRC. As previously argued, the information recommended by Article 7 would be beneficial for children to have and risky for them to be without. With the introduction of a lead-in period to provide prospective parents with plenty of notice of the introduction of the new laws, parents would be informed of their obligations and what penalties are in place in relation to the information required for the fulfilment of their child’s right. It is imagined that
following the lead-in period there would be no reason for surprises regarding paternity, for instance.

However it is recognised that cases of mandatory DNA testing like those carried out in Argentina are problematic because they force information on those who do not wish to know. Secret DNA testing was also considered to be problematic by the German government and many others. However, the problems associated with these countries can be counteracted by my paradigm shift to DNA testing newborn children and their alleged parents to identify genetic parentage. Unlike China and Argentina, who only DNA test some citizens or force information on adoptees, my proposal includes all alleged genetic parents and their children, thereby reducing the possibility of marginalising certain citizens. Furthermore, it levels the playing field for all children, as each child is tested and entitled to equal access to what information is available on their genetic parents. In addition, as previously stated, this information should be made available to children in such a way that they can refuse to have it if they so choose. Mandatory DNA testing is the best means of identifying genetic connections between parents and their children and there are a number of good reasons why the government should support this proposal, including the fact that they should honour those treaties that they ratify.

If some type of ‘exception’ form could be instituted to account for instances where it would not be in the child’s best interest to know the identity of her genetic father, for example, then this would help reduce risks for these mothers and their children. Again, it is thought that with a two year lead-in period, these sorts of problems would only arise on rare occasions. Even so, there should be an option available for those persons living in abusive relationships so that their lives are not impacted by paternity revelations.

Of course, this is not to suggest that there are no other problems with DNA testing newborn children and their alleged parents. It may be argued, for instance, that this option infringes certain of our individual—rights; the rights to privacy, for instance. Therefore, because this may be an issue, in the next chapter I discuss privacy concerns that may arise when collecting mandatory DNA samples for genetic parentage testing.
Privacy Concerns And Data Integrity, Part 1

So far I have discussed why we should collect information about genetic relationships between parents and children (children have a right to this information and it is beneficial for them to have it) and how this could be gathered (through DNA testing) and from whom (newborns and their alleged genetic parents). I next move to discuss the privacy concerns that prima facie attach to the collection of information about individuals, since there may be some concern that mandatory DNA testing of newborns to identify their genetic parents could invade their entitlements to privacy. While there are a number of ways in which a person’s privacy may be breached, I focus specifically on two ways this may occur in relation to DNA testing carried out to identify genetic parentage. Problems for individual privacy may occur either through non-consensual intrusion of an individual’s person or through disclosure of his private information without his consent. As DNA material contains personal information that people may wish to keep private, including their current and potential health status, collecting this type of information could pose problems for personal privacy.

In the first part of this chapter, I address privacy concerns in relation to non-consensual intrusion of an individual’s person and privacy concerns in relation to gathering genetic information. I focus on the current norms surrounding the protection of personal information. I also provide some discussion on the exceptional and essential nature of DNA. In the second part of the chapter, I address some of the risks associated with storing a person’s private information in a database.

Explanation

Personal information is described by the Privacy Act 1988 as “information or an opinion (including information or an opinion forming part of a database), whether true or not, and whether recorded in a material form or not, about an individual whose identity is apparent, or can reasonably be ascertained, from the information or opinion.” I take this to mean that personal information is information relating to an individual that could identify that person, which, of course, would include their name. Assuming that it is possible that other information about children and their genetic parents could be ascertained from their DNA profiles if they were contained in the database I propose, this raises concern about their personal privacy. To safeguard information we must treat it in accordance with the most

appropriate privacy principles available. Currently the data protection principles applied to
the collection of personal information are covered by the *Privacy Act 1988*. So, it is this Act
that I will focus on in relation to my proposed policy shift. I seek to determine if the
protections this Act provides are sufficient to protect the information I propose collecting and
also if my proposed policy can satisfy the requirements of this Act.

At this point, it should be noted that a database for parentage testing of newborns need
not include any other information in the profile other than the genetic connections between
children and their parents. It is my proposal that the DNA profiles for identifying genetic
parentage should be curtailed to this limited information, since this is the only purpose for
which I argue that it ought to be collected. Therefore, I propose that all DNA samples be
destroyed following testing and just the necessary information for my paradigm shift retained
as a profile of each child. This prevents further use of these samples, thereby reducing the
risks of additional information being obtained than that called for from DNA testing for
genetic parentage identification. There is no relevance to keeping this material and
information following the tests. Therefore, they should be destroyed completely. Furthermore, the information profiles destroyed should include all persons found to have no
genetic relationship to the child. This would help to reduce any privacy concerns for those
persons not genetically relevant to the information that is required for the fulfilment of
Article 7 of the CRC. Thus I will be arguing from the perspective that all samples following
testing are destroyed.

*Privacy Principles Relating To Collecting Personal Information*

Since it is necessary to collect certain personal information about people for a number of
reasons—the census is one example—it is vital that there be laws in place to protect people’s
personal information when they do not want it disclosed to others. Typically in Australia,
each state and territory is subject to its own rules and regulations. However, certain privacy
laws pertain nationally.  The *Privacy Act 1988*, following a number of amendments over
the years to take into account changes in the way we communicate information and advances
in technology, is the current law overseeing the data protection of personal information in
Australia. The *Privacy Act 1988* sets out a number of privacy principles that the public
sector must adhere to, known as National Privacy Principles (NPPs). The privacy principles

---

427 Australian Privacy Foundation, 2011, np.
428 Ibid.
that government agencies must adhere to are known as Information Privacy Principles (IPPs).\footnote{Ibid.} As I am proposing that a government agency or a government monitored and regulated agency be responsible for the collection, storage and maintenance of the information about children and their genetic parents, I provide a brief account of the current relevant IPPs that govern the collection of personal information in relation to government agencies. Simply stated, these principles require that:

(a) the information collected by agencies is necessary for the agencies’ work and must be collected fairly and lawfully;

(b) people be informed about why the information is being collected and what laws give authority for the collection of the data;

(c) persons be informed about whom the information will be disclosed to;

(d) the information gathered must be relevant, up-to-date and complete and must not be collected in an unreasonably intrusive way;\footnote{Office of the Australian Information Commissioner, 2008, p. 1.}

(e) individuals have access to their own personal information;\footnote{Ibid., p. 2.}

(f) where information is recorded incorrectly, this information should be able to be amended or corrected;\footnote{Ibid., p. 3.}

(g) information must be stored securely to prevent its loss or misuse\footnote{Ibid.} (I address the problem of storage in part 2 of this chapter); and

(h) information is to be used only for a relevant purpose.\footnote{Ibid.}

Taken that these IPPs are stated in their basic form, these privacy principles form part of the rules and regulations within Australia regarding the collection and storage of personal information that individuals may wish to remain private. Of course, these privacy principles cover more than the collection of DNA information, these privacy rules and regulations also govern such personal information as that relating to finances and credit reporting and so on.\footnote{Australian Legal Information Institute, nd, Part III.} So, there are a vast number of areas covered by the \textit{Privacy Act 1988}. However, I curtail my discussion to the basic privacy laws in relation to the information I argue is gathered on behalf of children. What is to be noted here is that there are norms currently in place that address privacy issues relating to personal information. The question is, of course, are these privacy laws enough to address the problems that may arise regarding the institution
of DNA collection about genetic parentage? To answer this question, I look at each of these privacy laws in turn in order to see if my policy shift can adhere to them and to determine if more stringent laws are required.

**Necessary Information Collected Fairly And Lawfully**

Addressing point (a) of the IPPs and taking into account the beneficial reasons for thinking that children ought to have the right to information about their genetic parents—for instance, health benefits; increased autonomy; identity; and self-knowledge; as well as the possible risks of children being without it—the avoidance of incest and so on, I argue that the information I propose collecting about genetic parentage is necessary information gathered in children’s best interests and in order that they can come to realise their right to this information as specified in Article 7 of the CRC.

Furthermore, if children have a right to information about their genetic parents, then at some point it will be necessary to collect it on their behalf in order that they may realise the fulfilment of this right. Since it has been shown that some parents are denying their children this information, then it seems necessary to collect it through DNA testing to provide to them at an appropriate age. As necessary information, collected in the best interests of children, my policy proposal would comply with the first part of IPP (a) to qualify as information that is permissibly collected in terms of individual privacy under the current privacy laws.

However, it is not enough that the information that is gathered is necessary information in order to comply with the Privacy Act 1988, the information also has to be collected fairly. Since my proposed paradigm shift calls for the acquisition of DNA from all newborns (perhaps with the exceptions of those cases noted earlier relating to incest and so on) and their alleged genetic parents for testing without distinction, this would comply with the second requirement of IPP (a) of the Privacy Act 1988. My proposed policy shift would comply because it does not make any distinctions among newborn children: all Australian-born children would be tested and would have this information available for them to access.

The problems of equality and marginalisation when data is collected about individuals were raised in relation to the British criminal DNA database (NDNAD). The NDNAD was set up to record the DNA of criminals in the UK. However, it also contains the DNA of those found not guilty of a crime. So, the obvious concern raised about this database is that if it was intended to contain the profiles of criminals, why are innocent people’s profiles being stored? Concern over this matter was raised in 2007 by Nick Clegg, then the Liberal Democrat Home Affairs spokesman, who said in a BBC new report that there was “no earthly reason” why
someone who has committed no crime should be on the database—“yet the government is shoving thousands of innocent people’s DNA details on to the database every month.”

Some perceive this issue as a conflict of people’s rights—the right of people to be protected from harm and their right to privacy when they are found innocent of a crime. This criticism of the NDNAD has lead to a number of challenges and attempts to remove names from it when a suspected criminal has been found innocent. For instance, in 2008, the inclusion of innocent people’s DNA in the database was successfully challenged in the European Court of Human Rights. However, despite this criticism and challenge to the database, “Police have been told to keep hold of as much DNA as possible until the law is officially changed by the Home Office.”

This has led some, such as Bob Williamson, director of the Murdoch Children’s Research Institute, to support DNA testing everyone in the UK. According to Williamson in an article by Tom Noble in The Age, there are “two fair possibilities for DNA testing—to test everyone or no one—and the former is better.” Williamson is of the opinion that “testing only a few in society made DNA testing seem a punishment, and when someone refused to volunteer for a test, it suggested they had something to hide.” This is an important point and would also be relevant in the case of DNA testing for genetic parentage. If DNA testing for genetic parentage were optional, for example, and a mother refused to have her child tested, it would look like she had reason to doubt the paternity of her child. This could lead the alleged father of the child and others to raise suspicions about the genetic paternity of the child and want to know why she did not want the child tested. This doubt could cause family problems. Suspicion about paternity of a child could impact the child, especially if the alleged father were abusive and jealous. This clearly would not be in a child’s best interest.

However, there are other problems with the NDNAD. In addition to containing the DNA of innocent people, this databank also seems to be recording the DNA details of certain members of the population, namely those ‘suspected’ of committing a crime. Lord Justice Sedley, one of England’s most experienced appeal court judges, said that storing the DNA of innocent people on the database was “indefensible and biased against ethnic minorities, and it would be fairer to include everyone, guilty or innocent.”

439 Slack, James, 15/01/2010, np.
440 Noble, Tom, 8/08/2002, np.
441 Ibid.
442 Ibid.
Lord Justice Sedley’s seems to be suggesting that it was ‘indefensible and biased against ethnic minorities’ because of what seems to be the over-representation of certain groups of persons in the NDNAD, which looks like particular groups of UK society are more inclined to commit crimes than others. On one interpretation of Sedley’s argument, it might be thought that the UK government have singled out and marginalised certain members of the community, if these members of the community were innocent; thus creating what appears to be inequalities between citizens. Of course, it may not actually be this way, but this interpretation could be drawn from the argument presented by Lord Justice Sedley against the collection of people’s DNA in this databank.

Whether or not this interpretation is correct, I would not recommend a system that appeared to marginalise anyone. So, I take these criticisms into account as one of the possible risks incurred in this type of data collection. Sedley’s solution, similar to Bob Williamson’s, is “to expand the database to cover the whole population and all those who visited the UK, even for a weekend.” Thus it should be noted, that rather than argue for a reduction in the number of DNA profiles in the databank, Sedley and Williamson proposed to solve these problems of the NDNAD by recommending that all citizens’ DNA be included in the databank. If the inclusion of all persons’ DNA in a database reduces some of the risks associated with unfairness and marginalisation of citizens, then my proposal of DNA testing all newborns is in accord with Sedley and Williamson proposal. My proposal, therefore, seeks to avoid the problem of unfairness and marginalisation that has been levelled at the British DNA database by DNA testing all children and their alleged genetic parents. This would ensure that the parentage database included all children’s DNA and not just some—namely those children whose parents agreed to be tested. The inclusion of all children’s profiles in the database would avoid claims of selectivity and marginalisation that could be claimed by those children whose parents objected to being tested. By collecting the DNA of all newborns and their genetic parents, eventually the details of all citizens would be in the database, thereby removing the possibility of unfairness and discrimination among citizens. Mandatory DNA testing of all children levels the playing field for all children. My policy proposal holds to egalitarian principles and, as such, would meet the requirements of IPP (a) for fairness, because it is inclusive of all Australian-born children and does not discriminate against, nor marginalise any child.

443 Ibid.
Furthermore, as previously proposed, this information should be gathered by a
government body or government monitored body as opposed to unregulated private
enterprise, because this would ensure, at the very least, that the information is collected
legally by agents under regulation and monitoring. Therefore, my policy shift could satisfy
the final part of IPP (a) and would comply with the Privacy Act 1988 for protecting
individual privacy when collecting DNA information.

As a result of its ability to be fair in its collection of data, and the fact that I only
advocate the collection of information that is necessary to identify genetic parentage of
children, my proposed paradigm shift could satisfy IPP (a) of the Privacy Act 1988 for
collecting personal information fairly and lawfully. Of course, what happens following the
collection and storage of the information raises other privacy issues, which I address in the
second part of this chapter.

**Inform People About Why Information Is Collected And The Laws That Give Authority**

IPP (b) of the Privacy Act 1988 relates to how well people are informed about the collection
of the DNA information. As previously stated, a lead-in period of at least two years should be
provided to citizens prior to instituting mandatory DNA testing of newborn children. This is
to ensure that all prospective parents are informed of the process and the fact that it will be
mandated at a certain future time. As previously stated, it would be wrong to introduce
mandatory DNA testing straight away, given that it could cause alarm for some people if the
results for genetic parentage were unexpected.

However, it is not enough just to inform people of the introduction of mandatory DNA
testing in advance, they should also be provided with information about the legislation
authorising the collection of DNA from their children and themselves, according to the
Privacy Act 1988. This information should include the fact that Australia has ratified the
CRC and that Article 7 of that convention provides children with a right to information about
their genetic parents—information that may only be acquired, in some cases, through DNA
testing. Identifying this requirement of the CRC would help people to come to terms with
their children’s rights and the duties and obligations that arise from them.

People should also be informed of any penalties that apply if they refuse to comply with
mandated DNA testing. In other words, people should be informed about the whole process
and what it entails. This is to ensure that there are no surprises for them and the process is
open and explicit; no changes to legislation should be introduced that are underhand or
covert. It is important that people are presented with all the facts so that they understood the rules and regulations. This makes it easier for people to comply with them.

Ensuring that people were informed of all stages of the process in advance would satisfy IPP (b) of the *Privacy Act 1988* for collecting personal information about individuals. Furthermore, it is only if full public disclosure of information regarding the process of DNA testing of newborns and their parents is a condition of gathering this information that I support this paradigm shift. For, if information regarding all processes of mandatory DNA testing were not provided to the public in advance, it could lead to citizens’ loss of trust in the government and the process of DNA testing for genetic parentage. People could, for instance, interpret the government’s failure to keep them informed of this paradigm shift as an attempt on the government’s part to conceal something from them, perhaps, a hidden agenda. This could lead citizens to object to the process of providing information about themselves and their children on the grounds that they were not provided with enough information prior to the process and they now doubt the government’s intentions regarding the collection of information about themselves and their children. It is necessary that people have faith in the process of mandated DNA testing and the openness of the government regarding why the information is being collected and the laws giving authority for the collection of genetic parentage information. Consequently, I propose that prior to introducing mandatory DNA testing for genetic parentage, that at least a two year lead-in period be provided and that people are made aware that mandatory DNA testing for parentage is coming into force and their obligations under the new proposal. Indeed, people should be given all the facts surrounding the process. If these measures were instituted, as I suggest they should be, my proposal would satisfy the requirements of IPP (b) of the *Privacy Act 1988*.

**To Whom The Information Will Be Disclosed**

According to IPP (c) it is necessary to specify to whom the information will be disclosed in order to ensure that others not authorised to have it do not gain access to it. Naturally, children, in the first instance, should have this information. So, they are the principle persons to whom the information will be disclosed. However, because it is sometimes necessary that personal information be disclosed to others, such as social parents, it is important that this information only be disclosed with the consent of the subject of the information. However, gaining consent from very young children and informing them about whom the information will be disclosed to is problematic. It is acknowledged that getting consent from children and
informing them of their rights and so forth is far from straightforward because, as previously discussed in Chapter 1, there is an issue of competency when discussing very young children.

Of course, as very young children are not autonomous beings, their rights are entrusted to their parents. Indeed, parents generally have to make decisions on their children’s behalf. For instance, when children are ill, their parents sometimes take them to the doctor and the doctor discloses the child’s health status to the parents. A child’s consent is not required for this information to be disclosed to her parents nor is their consent required for any inoculations against diseases that their parents may consent to on their behalf. This is generally considered to be in a child’s best interest. This is a not a controversial issue in the medical or philosophical fields. For instance, Dr. Jeffrey Hord, a practicing paediatrician, haematologist, and oncologist affirms, “In cases involving children, respect for autonomy is not seen in the same manner as in adults because young children often are not felt to have decisional capacity, which is a prerequisite for autonomy.”

The philosopher, John Locke best describes this subjectivity of children in his discussions on the equality of people.

Children, I confess, are not born in this state of equality, though they are born to it. Their parents have a sort of rule and jurisdiction over them when they come into this world, and for some time after; but it is but a temporary one. The bonds of this subjection are like the swaddling-clothes they are wrapt up in, and supported by, in the weakness of their infancy; age and reason, as they grow up, loosen them, till at length they drop quite off, and leave a man at this own free disposal.

It is, of course, assumed, as Locke suggests, that children will gain autonomy as they grow older and, it is further assumed, that if they had autonomy earlier that they would be asked to consent on their own behalf. As the very young cannot give their consent as to who will or will not receive their information, this should fall to their custodial parents while they are still children without decisional capacity. Thus custodial parents need to be among those who should be informed about their children’s genetic parents along with their children. This is so that they have the information to pass on to their children about their genetic parents. It also could allow them access to information about their child’s genetic health status and thus to take measures to promote their child’s wellbeing.

In addition, in cases of medical treatment and research there are provisions for overriding consent when consent cannot be obtained from the patient. For instance, Section 95A of the Privacy Act provides for such cases. It states, that Section 95A can be applied only in situations where it is “impracticable to seek consent from the individual(s) involved and it

---

444 Hord, Jeffrey et al., 2006, p. 5455.
445 Locke, John, 1690, pp. 414-415.
also must be that de-identified information will not achieve the purpose of the research or compilation or analysis of statistics activity."\textsuperscript{446} Given that children are unable to consent and that the information would need to be de-identified at the point of provision to the child, it seems reasonable to argue that my policy fits within this Section of the Act. Since there are provisions covering children and those unable to give consent in cases of medical treatment and medical research, I see no reason to think that this provision could not apply in the case of DNA testing for genetic parentage.

\textit{Argument Against Disclosure To Social Parents}

One argument against disclosing information to social parents is that providing information about the identities of a child’s genetic parents to her social parents could be considered a breach of her privacy. Of course, it is understood that when children have attained competency, it is they who would make the decision about whom the information will be disclosed to. This would help prevent a breach of their privacy.

However, while children are still young, this solution is unhelpful. One way to overcome the problem of consent to disclosure of information to social parents while still informing children would be to not make this information available to anyone other than the children themselves until they can consent to others having it. This solution has the advantage of preventing others from having the information, thereby better protecting children’s privacy. If presented in the form of a certificate, this could be accessed by the child when she shows a desire to have it and is mature enough to request it from the government agency on her own behalf.

I further suggest that the information gathered from DNA testing should be kept separate and distinct from other forms of information gathered on citizens. One reason for thinking that this information should be kept separate and distinct from other personal information, such as that contained on the birth certificate, for instance, is to ensure that it is not disclosed by accident to the child (in rape cases, for instance) or others not entitled to have it. Keeping it separate and distinct from a child’s birth certificate may help ensure this does not happen. As previously stated, some children may not want to have this information and it should never be forced on them.

Adopting this option also has the advantage of reducing the number of persons with access to the information. Because parents may need to present their child’s birth certificate

\textsuperscript{446} National Health and Medical Research Council, 2001, p.2.
for admittance to school, for instance, it is better that the two certificates be distinct and separate. This prevents others from gaining access to the information. Exposure of sensitive information could lead to stigmatisation and discrimination for some children. According to Margaret Everett, an anthropologist and sociologist who works in the field of bioethics, “‘Genetic privacy’ alludes to fears of discrimination, social stigma, self-identity, and psychological issues.”447 In addition, according to the bioethicist, Jeroen Van Den Hoven, in Information Technology, Privacy, and the Protection of Personal Data,

Many people do not object to the use of their personal medical data for medical purposes, confined to the medical sphere, whether these are directly related to their own personal health affairs, to those of their family, perhaps even to their community or the world population at large. As long as they can be absolutely certain that the only use that is made of it is medical. That is, to cure people from diseases. They do object, however, to their medical data being used to classify them or disadvantage them socioeconomically. To discriminate against them in the workplace, refuse them commercial services, deny them social benefits, or turn them down for mortgages or political office.448

This seems to support the view that people are not concerned with the use of information in its proper context, that is, the reason for which it was originally gathered. It is when we deviate from the context from which the information was gathered that we run into problems and concerns for personal privacy. As we will see this is in line with Helen Nissenbaum’s view, which I will return to shortly.

If the information I call on to be collected can be properly protected from disclosure to those not authorised to have it, then I see no reason why a child could not obtain a certificate, for instance, identifying his genetic parents when he attains a certain degree of autonomy. It is generally recognised, as Prof. Tom Campbell points out in The Rights of the Minor: As Person, as Child, as Juvenile, as Future Adult, that “As a juvenile the child has considerable autonomy interests and many of the rights of the child may be seen as recognizing this fact.”449 In addition, Campbell notes that “Certainly it is hard to see any rationale in terms of capacities and interest in the extensive and variable limitations placed on the freedoms and powers of adolescents.”450 If the child displays clear signs of maturity on a par with the lowest attained capacities of adults,451 then there is no reason why the child should not be considered mature enough at that stage to access this information, which has been gathered

447 Everett, Margaret, 2004, p. 277.
450 Ibid., p. 18.
451 Ibid., p. 19.
on his behalf and in response to his right to have it. The tenacity of the 17-year-old American Minor J, as previously mentioned in chapter 4, who attempted to sue his mother in a court of law to determine the identity of his genetic father, is a case in point. Even though Minor J failed in his endeavour in the American courts, clearly his attempt shows that some juveniles are mature enough to claim their right to information about their genetic parentage through their own autonomous capacity. So, there is an argument to be made that it is unnecessary to include social parents among those who should have access to information about a child’s genetic parents; children can obtain this information for themselves when they have attained the autonomous capacity to do so.

**Argument In Support Of Providing Information To Social Parents**

However, one problem with withholding genetic parentage information from the child’s social parents is that doing so may prevent the child from receiving the full benefit of her right as expressed in Article 7. Withholding information about a child’s genetic parents until the child reaches her own autonomous capacity risks her being denied access to information about her genetic parents’ family medical history. In my view, it is generally better for parents to have genetic family medical information about their children so that they can take steps to address their children’s healthcare. Doctors disclose information about children’s health to their social parents. So, if children’s medical records can be disclosed to their social parents without breaches to their privacy in order that social parents may attend to their children’s best interests regarding health care, then there is no reason to think that information about a child’s genetic parents’ health history should be considered any different. After all, health benefits are one of the reasons for thinking it important that children have information about their genetic parents, as previously discussed. As it is beneficial for the young child that her social parents have access to information about her genetic parents, then, in the child’s best interest, it is necessary to discount her right to sole access of this information until she attains decisional capacity.

Furthermore, as already shown, if the information is held until a child reaches maturity, then there is the possibility that she may suffer genealogical bewilderment or unknowingly form consanguine relationships with a sibling or half-sibling. Therefore, as previously argued, it would be better that she be given this information at a young age. This means that her social parent would need to have this information in order that these risks can be avoided. Thus, custodial parents, it would seem reasonable to think, ought to be among those to whom this information should be provided.
Of course, a separate certificate containing the necessary information should still be issued to children when they attain maturity as a precaution against their custodial parents refusing to divulge this information to them. While children and their social parents should be among those to whom the information should be made available, others too may need this information.

**In Support Of Providing Information To Genetic Parents**

As has been argued above, social parents should be among those to whom the information is disclosed. However, it is also thought that genetic parents would also need to be provided with information regarding their genetic connections to their children. This is so that they would be informed about those children to whom they have genetic connections. Genetic parents need to be informed about their obligations requiring them to provide the necessary information about themselves so that their children can access this information at a future date. Parents not informed of their genetic connections to children would not be aware of their obligations in this respect and, as a result, may not fulfil their obligations. This could result in the right expressed in Article 7 of the CRC remaining unfulfilled for some children. Thus it is thought that genetic parents should be among those who are informed of the results of their DNA tests linking them to their children and their obligation in respect of those children to provide information about themselves.

**In Support Of Providing Information To Those Found Not To Be Genetically Related Following Testing**

It is further thought that those who are eliminated as genetic parents of children should also be told the results of their tests, although it is not necessary to inform them who the genetic parents are. While some may be upset by and others happy with the results of the genetic parentage tests, by informing people about their non-genetic links to children, this would put an end to suspicion and doubt about this matter. Informing those who are not genetically related to children following DNA testing for parentage, would acknowledge that they have no obligation to provide further information about themselves. Furthermore, there should be no attempt to record their information on the database once they are shown not to be genetically related to a child.

This would reduce or eliminate the risks to privacy breaches for those with no genetic links to children, since their profiles would not be contained in the database once they were proven not to be genetically related to a child. This would reduce the number of those at risk
of privacy breaches through genetic testing for genetic parentage. Of course, if it was shown that they had genetic links to another child in the database, they should be informed of this, if they are not aware of this already. It is assumed that a database could make these connections if designed to do so. These people should be informed about their genetic connections to children because they are obligated to provide their identities to those children. Additionally, their information should be recorded on their children’s profiles.

Why Informing Those Tested Is Beneficial

Of course, while retaining information about those parents who have genetic links to children in a database poses a privacy risk for those genetic parents and their children, informing these parents of their genetic parentage status would explain why their information is being retained and their obligations as addressees of Article 7 of the CRC. In addition, by providing those who test positive for genetic parentage with the results of the tests, this allows them to consent to or to withhold consent to others than those entitled to the information having this information and it allow genetic parents to control the amount of information flow in the form of vetoes, for instance.

If those involved in the DNA process are not informed of the results of their genetic tests, they will be in no position to follow through on their obligations or to control the flow of information or to decide who their information should be provided to. Therefore, it is in everybody’s interest, who partakes in DNA testing, to know the results of their tests.

By specifying only those that would have access to the information, this would help control the flow of that information and, thereby, prevent the information being disclosed to those not authorised to have it. (I address data-mining issues in the next part of this chapter). By identifying and specifying all those to whom the information ought to be disclosed, my proposal would meet the requirements of IPP (c) of the Privacy Act 1988 and would help ensure that only those authorised to have the information I call for could gain access to it.

Up-To-Date, Complete Information

The information identifying a child’s genetic parents is valuable for children to have for a number of reasons, as previously discussed. However, it is only an accurate and up-to-date account of genetic relationships between genetic parents and children that I support. As I support parentage testing using only the very latest technology available at the time of the birth of the child, the information obtained should be always accurate and up-to-date. DNA testing provides as complete and accurate an account of a child’s genetic parents as is
currently possible to achieve. EasyDNA Australia, much like all other DNA testing facilities, offers 99.99% accurate testing, although, at $295 per do-it-yourself test kit, these results are not admissible in courts of law. However, for a fee of $595, the purchaser can obtain test results that are admissible in court. The higher costs involved in DNA testings for court proceedings reflects a strict “chain-of-custody” procedure that must be followed to ensure that the samples do not become contaminated and can be verified as belonging to the persons being tested. This generally means that the samples have to be taken by a doctor or specialist and maintained in a strict uncontaminated environment until the test results are produced. This is to ensure that the evidence can be relied upon to stand up in legal proceedings. Hence, the costs incurred for carrying out these particular tests are higher.

Consequently, to be absolutely certain that genetic parentage is accurately identified, both genetic parents and their children need to be tested in a controlled environment following a strict chain-of-custody procedure. I only support mandatory DNA testing where these strict procedures are undertaken, as the results of mandatory DNA testing should be able to stand up to scrutiny in a court of law. Anything less than complete accuracy in the results could cause parents unnecessary problems as a false result could seriously damage family relationships. People ought to be confident in the results of mandatory DNA testing to identify genetic parentage so that they are willing to comply with testing.

Of course, if science and technology were to improve beyond today’s standards for collecting DNA information about a child’s genetic parents, it is expected that the methods of collecting would improve accordingly. This would help ensure that the information gathered was always up-to-date and as complete and accurate as it could be, helping to satisfy IPP (d) of the *Privacy Act 1988*.

**Methods Of Testing For Genetic Parentage That Are Not Unreasonably Intrusive**

As previously stated, one benefit of DNA testing to establish the identities of a child’s genetic parents is that it can be carried out using non-invasive methods. I have also highlighted a number of ways that non-invasive samples can be gained using biological fluids from the child along with the same sorts of biological DNA samples from her alleged genetic parents.

---

452 easyDNA Australia, 2006, np.
453 Ibid.
454 Ibid.
455 Ibid.
456 Ibid.
Since obtaining samples of DNA for testing does not require invasive procedures, and since testing of any samples of a child’s biological material would give the same accurate result—provided that samples are not contaminated—there is no reason to use invasive methods to carry out DNA tests to identify children’s genetic parents.

Furthermore, because biological samples containing DNA can be obtained by non-invasive means, we avoid intrusive methods and, thereby, my policy shift would satisfy the requirement of IPP (e) of the Privacy Act 1988 for collecting personal information. It is understood that children, were they able to be consulted on this matter, would want this information collected on their behalf. This is based on their testimonies presented in chapter 4. Therefore, the information would be collected through assumed consensual, non-intrusive means.

**Individuals Should Have Access To Their Own ‘Personal’ Information**

Naturally, access to children’s own personal information is the primary subject of this call for a paradigm shift to mandatory DNA testing. It is a child’s right to this information that the CRC promotes. It would make no sense to obtain this information, therefore, unless children are provided with a legal right to it upon request. While it is hoped that social and genetic parents would themselves provide this information to their children, the fact that in some cases this will fail to happen means that children should gain access to this information at some point in their own right through other means—on my view, following mandatory DNA testing.

Children should be able to access this information because it is information about them, collected for their benefit, with their best interests in mind. Children should have access to this information in order to benefit from the goods it provides and to avoid the risks of being without it. My policy shift recommends that children be provided with access to this information, which would satisfy IPP (f) of the Privacy Act 1988. Indeed, once it has been collected for their benefit with the aim of identifying their genetic parents, it would be a breach of their privacy entitlements according to the Privacy Act 1988 to prevent them from having access to it.

**Where Information Is Incorrectly Recorded**

In order to satisfy principle (d) of the Privacy Act 1988 it is essential that information is accurate and up-to-date, as previously discussed. While it is expected that using current technology to gain information from DNA samples would always result in an accurate
account of the facts (DNA testing to determine parentage of children provides 99.99% accuracy in determining paternity and is 100% accurate in determining non-paternity), given that information may be recorded incorrectly on occasion, it should always be possible to have errors rectified. As it is essential that DNA information about genetic parents be correct at all times, where information is recorded incorrectly, this information should be able to be amended or corrected as soon as possible. Errors in recording or inaccurate information can be a source of concern as it could cause family problems if the wrong father was recorded, for instance. This would not be in a child’s best interest. Therefore, only a completely accurate account of children’s genetic connectedness to their genetic parents is acceptable; anything less could cause untold problems for families. Having the ability to correct wrong information is necessary to satisfy privacy principle (g) of the Privacy Act 1988, a principle that I fully support and recommend in all instances of information gathering on people. Presenting children with incorrect information about their genetic parents defeats the purpose of gathering that information in the first place.

**Information To Be Used Only For The Relevant Purpose**

In regards to complying with IPP (h) of the Privacy Act 1988, it is important that the information that is collected is relevant to the purposes for which it was collected, in this case for the identification of genetic parents of children. For this reason, the information that is collected should only contain what is necessary to identify the genetic connections between parents and children. Aside from information about the identities of the genetic parents of children, no other information should be gathered from the DNA samples, and the samples themselves, as previously stated, should be destroyed following testing. This is to ensure that no further use can be made of them. This is to prevent the information from being used for other purposes than the one intended, that is, the one I am proposing.

Although I am calling for DNA testing of alleged genetic parents to identify the actual genetic parentage of children, this does not mean that information about those genetic parents’ health or any other information about those parents should be gathered. This is to ensure that only the relevant information for my policy is collected. And, even though other information about genetic parents would be useful for children to have, I do not recommend that this information is collected from the genetic parentage DNA tests that I propose. This is to ensure that only the relevant information to address the right I argue for is retained—identities of genetic parents. Health information, it is understood, can be sensitive information for several reasons, including for potential employment reasons. As a
consequence, I advocate that the identification of genetic links between parents and children be the only information that is stored in a database. The information about a child’s potential genetic health status and the number, identities and ages of sibling and half-siblings (if known), it is thought, should be provided by the genetic parents. This information could be left by genetic parents for their children to access themselves. While I have argued that this information is important for children to have and would be available to them if they were raised by their genetic parents, their right to this information is not stipulated in the CRC. Therefore, I confine my focus to their right to know the identities of their genetic parents, which is stipulated in the CRC.

Naturally, it is essential that information gained through DNA testing for parentage is used only for the purposes for which I am suggesting it is collected, namely, to establish information about the identities of children’s genetic parents in order to fulfil their right under Article 7 of the CRC. The use of these DNA samples for other purposes without the consent of the subjects, who provide it, would be in breach of their rights to privacy and this is not something I would support. Assuming, for the moment, that the information was used only for its intended purpose, this would suggest that my policy proposal could comply with IPP (h) of the Privacy Act 1988. However, noting that there is a possibility that data-mining may occur and that the current laws provided by the Privacy Act 1988 may not be up to protecting genetic information, I come back to this issue in the next part of this chapter.

In the discussion in this chapter, I have focussed on the ability of my proposal to comply with the IPPs of the Privacy Act 1988. However, some may think that this ACT is insufficient protection for the privacy of an individual’s information gained via DNA testing.

**Similarities To Information Already Collected**

One reason for thinking that information about a child’s genetic parents does not pose any greater threat to privacy than other information that is collected about them, is that this information is supposedly already collected and held by government. Since every child born in Australia is supposed to be registered at birth, a record of any particular birth would, under most circumstances, include the identities of the child’s genetic parents. Insofar that this is the case, it could be argued that a record already exists of most children’s links to their genetic parents. So, my proposal would not involve collecting information about people that is not already supposedly collected by government agencies, remembering too that this information is collected under the regulations and guidelines pertaining to the Privacy Act 1988. Generally speaking, the information on birth certificates could be considered as
information in the public domain in that it is already out there on public record. What is
understood here by public record is information that is accessible by the public. While it is
recognised that birth certificates can only be obtained by certain individuals during the
lifetime of a person, after a certain period has passed following their death, the records of
their birth, marriage/s and death are publicly available. This is how online companies like
Ancestry.com, for instance, can obtain and provide information to people about their
ancestors. Thus while a person is alive their birth and marriage certificates are quasi-private,
in that some people have access to them (such as the person whose birth certificate it is, their
genetic parents, step-parents, social parents and the police, for instance, conducting criminal
investigations), following a certain period after their passing, these certificates become
accessible to other members of the public. It is in this sense that, in my view, birth, marriage
and death certificates can be considered public records.

If information is in the public domain, then it ‘is up for grabs’ as highlighted by Helen
Nissenbaum in Privacy In Context: Technology, Policy, and the Integrity of Social Life
(2010). Information that is ‘up for grabs’ is problematic for my proposal, if the information
I propose collecting is thought to be too sensitive to be ‘up for grabs’, if it is information that
people would prefer, perhaps, was not disclosed to others, if it was information they thought
ought to be kept private and out of the public domain.

Of course, it could be argued that DNA information is nothing like the information
contained on a birth certificate and that it is more akin to medical information. If this is true,
then the current norms for protecting medical information should suffice for protecting
information about genetic parents, unless, of course, DNA information is considered
somehow different to other medical information.

**Distinctiveness Of The Information I Propose Is Collected**

Besides the argument that the information I propose collecting is personal and private and,
therefore, distinctly different from the information on a birth certificate, the fact that the
information is obtained from DNA samples, as opposed to the way information is gathered
for a birth certificate, is another important distinction between the two. Information gathered
for a birth certificate, for instance, comes from information provided by the genetic parents
(or clinicians in the case of donor-conception or carers in the case of orphans and so on). I, of
course, am proposing the use of DNA testing to provide information about genetic parents.

\[457\] Nissenbaum, Helen, 2010, p. 100.
So, the important thing that is different about my proposal and the information that is on a birth certificate is the method of collecting the information. Of course, DNA testing for genetic parentage could include the same information that is recorded on a birth certificate and most often will, if DNA testing for genetic parentage ever becomes mandatory. However, DNA testing provides an actual account of genetic parentage, whereas a birth certificate sometimes does not—following adoption and donor conception, for instance, as previously discussed. So, the third thing that is distinctively different between my proposal and the information that is collected for a birth certificate is that the information I propose collecting is factual information that may not be known without the use of DNA testing. This information may not already be recorded and may never be recorded in some cases without the aid of mandatory DNA testing. Therefore, the information that I propose collecting is distinctive, in yet another way, from the information recorded on a birth certificate, in that it is factual information that would not otherwise be recorded, in some cases, without mandatory DNA testing.

Fourth, DNA testing can produce data that could be used to record health status and a number of other things about a person—their race, their gender and their genetic relationships and so on. While it is possible to identify a person’s race and gender from their birth certificate, it is not possible to obtain information about an individual’s health status, for instance, from the way information is obtained for a birth certificate—usually a form filled in by the mother at the hospital following the birth of her child and sent off to the birth registry office. The means of obtaining information for a birth certificate does not carry a potential risk of exposure of a person’s health status. As a result, the method that I propose for collecting information, that is, DNA testing, has the ability to produce other information, which the method of gaining information for a birth certificate does not.

Thus there are a number of distinctions that can be drawn between the information gathered for a birth certificate and the information I propose collecting, the distinctions being in the method of obtaining the information; the information itself and its capabilities of identifying other things about a person, including current and potential health problems and genetic family connections.

The information I am proposing is gathered, in and of itself may not cause privacy concerns for most people—given that for most people this will be the same information that appears on their child’s birth certificate. However, even people who do not object to the collection of this information to identify their connectedness to each other may still have concerns about their privacy when this information is collected via DNA samples. This is
because of the capabilities of DNA to identify other thing about them. This would suggest that my proposal would not fit easily into the public sphere of information gathering. As a result, the information privacy principles that apply to the public sphere may not be sufficient to protect the privacy of the individuals that would be DNA tested for parentage under my proposal.

If there are distinctions between the information that is already collected for a birth certificate and the information that I propose collecting sufficient enough to warrant greater privacy protections than that awarded the public sphere, then it would be better to consider this information as part of the private sphere rather than the public one. In contrast to information that is considered to be in the public domain, information in the private domain is thought to be private and off limits. Information in the private domain could include family conversations in the privacy of their own home or information shared between doctor and patient, for instance. Given that the information I advocate be collected could be considered private information in this latter sense, this may suggest that it should fall into the private domain, rather than the public domain. After all, this information may contain sensitive information, information that parents and children may not want others to be able to access, in a similar way to their medical information. However, one problem with this view is that DNA has the capabilities to identify connectedness to other family members, which seems to go beyond the information generally provided to a family doctor. If we accept that the information I propose collecting is sensitive private information, then this would suggest that there was a distinction between my proposal and the information that is already collected, such as the information on a birth certificate or the information that we would normally provide to a family doctor.

In addition, while it may be possible to contain the information that is disclosed to close family members and friends in the home and within the doctor’s surgery, it may be harder to contain this information when a number of others outside the household and doctor’s surgery also require this information, such as the genetic parents of an adopted child, in order that they can fulfil their obligations as addressees of the right articulated in Article 7 of the CRC. This seems to suggest that the information I call for collecting does not fit easily into the private sphere either.

So, in order to address the privacy issues that may arise and to obtain the best possible solution to protecting genetic parentage information, we need an approach that does not depend on the private and public dichotomy. Helen Nissenbaum proposes such an approach.
Helen Nissenbaum And Contextual Integrity

Nissenbaum proposes that we adopt the view that focuses on privacy in relation to context when seeking to identify where problems of privacy may arise. It seems to me that when we understand where problems can arise for personal privacy, then we can take steps to solve them in advance. One of the problems that has been identified with my proposal is that it advocates the collection of new information in a new way to that gathered for a birth certificate. Nissenbaum proposes a contextual integrity approach to understanding the source of concern when collecting new information about individuals. Her reasoning is that

Contextual integrity can be applied to troubling but ubiquitous practices in the commercial marketplace of aggregating far flung information, developing identifiable dossiers, classifying consumers on the basis of information profiles, and targeting them for particular treatment on the basis of these chains of analysis.\(^{458}\)

I take this to mean that by considering the context in which information is gathered for dissemination and, by maintaining this context for information flow, we can identify what needs to be done to achieve information integrity. The closest context that I can associate my proposal with, other than a birth certificate, which for reasons stated above proved problematic, is a medical one, although this also proved problematic. However, between the two, a medical context is the best suited. I believe it is best suited to my context because medical personnel, in my view, should collect the DNA samples for testing in a non-contaminated environment. I imagine, this would be done in a hospital setting. However, the context in which it is stored for distribution to the recipient, would, I presume, be a public one—its closest equivalent being a birth certificate. Here I provide a brief account of Nissenbaum’s framework for contextual integrity. According to Nissenbaum’s framework,

Finely calibrated systems of social norms, or rules, govern the flow of personal information in distinct social contexts (e.g., education, health care, and politics). These norms, which I call context-relative informational norms, define and sustain essential activities and key relationships and interests, protect people and groups against harm, and balance the distribution of power. Responsive to historical, cultural, and even geographic contingencies, informational norms evolve over time in distinct patterns from society to society. Information technologies alarm us when they flout these informational norms—when, in the words of the framework, they violate contextual integrity.\(^{459}\)

Nissenbaum seems to be suggesting here that norms governing the flow of personal information, which she refers to as ‘context-relative informational norms’, have evolved over time to reflect a number of social concerns and interests in respect of protecting people and

\(^{458}\) Ibid., p. 211.
\(^{459}\) Ibid., p. 3.
groups against harms and in order to balance the distribution of power. It is only when
information technologies flout informational norms—when they violate contextual
integrity—that they alarm us.

One of Nissenbaum’s ways for monitoring concerns in relation to context-relative
informational norms concerning personal privacy is to note down if the proposed new system
is adding anything new to the information already available. “Locate applicable entrenched
informational norms and identify significant points of departure.”460 As I am calling for the
inclusion of information collected from DNA samples, to ensure that children have the
correct information about their genetic lineage, and not just information that is presented on a
birth certificate, this introduces something new to the information that is already collected for
a birth certificate. Thus my proposed policy shift comes under scrutiny because it departs
from the current norms for collecting information and it produces new information about
people that may not already be known, information that, in some cases, they do not know
about themselves. (How to address the problems associated with these departures from the
norm will be discussed in the next section). The capability of DNA to produce such sensitive
information about us has led some to consider DNA information as essentially who we are. If
that is so, then there would be a need for greater data protection measures than that provided
other medical information.

**Genetic Essentialism**

There is a view that we are to a large extent shaped by our genes (genetic essentialism).
Those that take this view are of the opinion that we are essentially our DNA. A genetic
essentialist may argue, for instance, that the importance of treating DNA as exceptional is
that we are essentially our genes. This view may be influenced by Bouchard’s latest research,
which I discussed earlier, which suggests that genetic heritability may account for a number
of individual qualities, such as IQ, personality traits, artistic interests, attitudes, and
religiousness.461 The importance of DNA on the essentialist’s view is that since we are
essentially our genes, then this would indicate that our health, our personality, our appearance
and so on are all influenced by our genes, accounting very much for who we are as persons.
This leads to the conclusion that if you want to know a person, then this could be achieved
through DNA testing. If genetic essentialism is correct, then this would suggest that

460 Ibid., p. 182.
information collected on our genes has the potential for greater harms through exposure than our non-genetic medical information. This is because, on this view, DNA can identify essentially who we are as persons, whereas non-genetic medical information obtained in the normal way through face-to-face contact with the family doctor pertains only to those conditions I present to the doctor, not my religion or other genetic family relationships, for instance. This generally seems to be the case; for when I go to the family doctor, he is usually unable to diagnose what is wrong with me unless I present the symptoms. Furthermore, the family doctor has no access to information about my other genetic family members unless and until I tell him who they are, or he already knows my family. On the other hand, a DNA test has the potential to reveal these things about me. Therefore, DNA testing has the potential to reveal more about me than would be revealed through non-genetic medical information. DNA testing can reveal more information about a person than would be required for my paradigm shift.

**Arguments Against Treating Genetic Information as Essentially Who We Are**

However, there are problems with the genetic essentialist’s view. The main problem with the this view is that it reduces us to our genetic components when many think we are so much more than this. Opponents of this view argue that we are, perhaps, placing more importance on genetic information than it warrants or deserves. One argument against the idea of genetic essentialism is the view that when it comes to our state of wellbeing, for instance, environment and diet can also play a role in health, as previously stated.\(^{462}\) We already know, for instance, that living in an environment where smoking cigarettes is a regular event can lead to potentially deadly respiratory problems for people who have to be in that environment—known as passive smoking—even if they themselves do not smoke. If the environment can affect a person’s state of health as fatally as her genetic makeup, then clearly we are just as dependent on the right external factors in our quest for good health as we are on our DNA. This suggests that while DNA may be a marker for potential health problems, it is not the only marker. Diet and lifestyle may also be important markers for our state of health—excessive consumption of alcohol and fatty foods is not conducive to healthy living even when our genes are devoid of genetic health risks. This leads to the conclusion that there is more involved in our constitutional makeup than just our DNA. Clearly things like diet impact our state of health. If we were essentially our genetic material, then outside

\(^{462}\) Hall, I. P., 1999, p. 68.
influences ought not to have any great impact on us. While there is some evidence to support the genetic essentialist’s view, clearly we are not fully expressed as persons in our genes. We may be partly influenced by our genes but we are not fully so. As a result I am not fully convinced by this theory. However, connected to this view is the argument that DNA is exceptional. This argument is more convincing.

**Genetic Exceptionalism**

Some people think that DNA information is importantly different from medical information. They think that DNA information is in some way special. This view is called genetic exceptionalism: the idea that genetic information is unique or exceptional in some way. Supporters of genetic exceptionalism argue that our DNA or, more precisely, information contained in our genes, is exceptional. One supporter of genetic exceptionalism is the bioethicist George Annas, who argues,

> In privacy terms, genetic information is like medical information. But the information contained in the DNA molecule itself is more sensitive because it contains an individual’s probabilistic “future diary,” is written in a code that has only partially been broken, and contains information about an individual’s parents, siblings, and children.\(^{463}\)

On Annas’ account, genetic information is exceptional in that, unlike other health information, it can provide probabilistic health status information; it contains information that is not currently fully understood by medical practitioners; and it contains information that could be used to identify not only the individual whose DNA it is, but also other genetic family members. For these reasons, collecting DNA information can be more of a risk to personal private information than collecting other non-genetic medical information. This suggests that the policy I propose of collecting DNA samples could reveal things about a child and her genetic parents that it may be better were kept unknown. Therefore, failure to provide stringent protection of this information could impact their privacy. Should the information I propose is collected be used for reasons other than that I suggest it is collected for, this could lead to a breach of people’s privacy rights, which in turn could lead to discrimination and stigmatisation for those whose information is collected. For instance, information about her or her genetic parent’s health status could fall into a potential employer’s hands and prevent her or her genetic parents from gaining future employment or it could fall into the hands of an insurer and prevent the child and her genetic parents from

\(^{463}\) Annas, George, 1993, p. 2346.
gaining insurance cover if it were thought that they had or could develop some genetic condition at a later date and they were considered a risk for a payout by an insurance company or employer, for example. Thus risks to privacy, although distinct from discrimination and stigmatisation, can lead to situations that pose potential risks of discrimination and stigmatisation for those whose information is collected via DNA.

For this reason, stringent privacy measures are advocated by Andrea de Gorgey, another who thinks that genetic information is importantly different to other health information. In her paper, *The Advent of DNA Databanks: Implications For Information Privacy*, de Gorgey discusses the collection of DNA information in criminal databases and the potential risks to the privacy of those whose DNA is tested. She states, “In this age of interlocking databases, it is possible that the hereditary information revealed in the DNA print could be used by employers, insurance companies and others for purposes beyond legitimate law enforcement.”\(^{464}\) She further states, “These samples could yield extraneous information about the individual, such as evidence of AIDS, drug use, past infections, familial relationships and genetic predispositions to various diseases.”\(^{465}\) For instance, if the collection of DNA from the alleged genetic parents and children also exposed a potential or actual medical condition (not information I am calling on to be collected, but which could be ascertained from the DNA samples prior to their being destroyed and this practice were not proscribed against), this could affect their chances of future employment if, for instance, this information was disclosed to their future employer/s without their consent. For those whose potential rather than actual medical status was being considered, this could lead to discrimination and stigmatisation. The risks associated with the probabilistic capabilities of DNA are a concern because they could cause harms, not only for the child; whose future employment, for instance, is at risk, but also for all those whose DNA is collected.

In addition, through data-mining (which I discuss further in Part 2 of this chapter, the information could be used to draw conclusion about people’s race or ethnicity or, indeed, their other genetic family members, such as grandparents and siblings. Thus potential risks for a child are also potential risks for her genetic parents and other genetic family members.

If genetic information carries these potential risks to people’s privacy, then this raises the possibility of greater harms occurring to persons than would otherwise take place from collecting other information, such as the information on a birth certificate or medical

\(^{464}\) De Gorgey, Andrea, 2005, p. 382.

\(^{465}\) Ibid., p. 388.
information, for instance. These possible risks that may occur through collecting DNA information, it thus could be argued, distinguish it from other medical information and thus suggest that it is exceptional.

If DNA information is exceptional, as genetic exceptionalists contend, then collecting and storing it would pose a great risk to children’s privacy and that of their genetic parents than that posed by collecting and storing their medical information, for instance. Annas further claims that the “Current rules for protecting the privacy of medical information cannot protect either genetic information or identifiable DNA samples stored in DNA databanks.”  

While I do not call for the retention of DNA samples, I accept his criticism of the current rules protection the privacy of DNA information, since prior to being destroyed these samples are a potential risk to people’s privacy. Furthermore, de Gorgey states, “The concurrent rise of genetic technology and the computer age calls for adequate safeguards to ensure that extremely personal information collected for a specific and limited purpose is not put to multifunctional use.” If Annas and de Gorgey are right, then it may be wrong to put children’s privacy at risk by collecting DNA information about their connectedness to their genetic parents without first instituting stringent protections on the data.

If genetic exceptionalists are right, then there is an important distinction between DNA information and non-genetic medical information and this suggests that there could be a need to treat this information differently, more stringently, in fact, than other non-genetic medical information in order to prevent potential harms to those DNA tested to identify the genetic parents of a child, even when it is only used to eliminate them as potential candidates.

**Arguments Against Treating DNA Information As Exceptional**

On the other hand, the clinical medical ethicist Lainie Friedman Ross in, *Genetic Exceptionalism vs. Paradigm Shift: Lessons From HIV*, argues against the idea of treating genetic information as exceptional on four grounds:

1. that this is not the only instance where stigmatisation and discrimination occur;
2. that genetic information raises no new ethical, social, or legal issues, but only highlights concerns that already exist;
3. that genetic information is not immutable; and

---

466 Annas, George, 1993, p. 2346.
4. that genetic information is not always probabilistic.\textsuperscript{468}

Friedman Ross argues that genetic information ought not to be treated as exceptional because it is no different to other medical information.\textsuperscript{469} One important point that Friedman Ross raises is that the predictive powers of genetic information is not unique to genetics. She argues, “Some observable diagnostic conditions may equally, if not more so, serve as disease predictors (e.g., high blood pressure).”\textsuperscript{470}

In regards to the claims that genetic information can lead to stigmatisation and discrimination Friedman Ross argues that “many assumptions are made about persons based on their race, sex or gender, ethnicity, age, and marital status”\textsuperscript{471} and that threats of discrimination and stigmatisation “exist as long as there are differences, and these may or may not have a genetic basis. Rather discrimination and stigmatisation of persons can be based on their religion, language, or culture.”\textsuperscript{472} Furthermore, according to Friedman Ross, we will never be able to remove differences between us, so long as there are differences between us.\textsuperscript{473} On this view, there will always be discrimination and stigmatization of persons as long as there are differences between us, that is, with or without the collection of information about genetic parentage.

In addition, Friedman Ross argues “that policies and practices that promote genetic exceptionalism are not morally justifiable because genetic information is not qualitatively different from other medical information.”\textsuperscript{474} While she acknowledges that “Genetic information raises important questions about privacy, confidentiality, [and] the legitimate interests of individuals in the medical information of others”, she argues against treating this information as unique to genetics.\textsuperscript{475} She states: “That genetics is non-exceptional also has major implications for health policy. These policy issues, however, cannot be treated as unique to genetics.”\textsuperscript{476}

Friedman Ross also argues that genetic information is not definitive because although mutations do occur in genes, for many genetic conditions, disease expression is influenced by other genes and by the environment.\textsuperscript{477} In addition, mutations occur in genes despite having

\textsuperscript{468} Friedman Ross, Lainie, 2001, p. 143.
\textsuperscript{469} Ibid., p. 145.
\textsuperscript{470} Ibid., p. 144.
\textsuperscript{471} Ibid.
\textsuperscript{472} Ibid., p. 142.
\textsuperscript{473} Ibid.
\textsuperscript{474} Ibid.
\textsuperscript{475} Ibid., p. 145.
\textsuperscript{476} Ibid.
\textsuperscript{477} Ibid., p. 143.
no genetic predisposition for doing so. For instance, a baby can be born deaf as a result of a flawed gene passed on from his genetic parents, or a child could suffer deafness or hearing problems if she is exposed to certain diseases in utero, including rubella (German measles), influenza and mumps.\textsuperscript{478}

Furthermore, according to Friedman Ross, the problem of treating genetic information as probabilistic is that sometimes genetic information is definitive, for instance, “the likelihood that if one has the gene, one will get the disease” is almost 100\% in cases of Tay Sachs disease and Duchenne Muscular Dystrophy.\textsuperscript{479}

Of course, it is not the case that Friedman Ross is seeking to ignore the importance of protecting the privacy of genetic information, but rather that she is seeking to have all medical information treated, not just genetic information, as equally deserving of the most stringent protection. Friedman Ross argues,

\begin{quote}
Health policies need to be designed to protect all of our health-care information and to promote all of our health-care interests; a patchwork system that gives additional protections only to genetic concerns is not a morally desirable solution.\textsuperscript{480}
\end{quote}

Indeed, it has to be agreed that personal, health-care information, no matter how it is obtained, should be protected through the best means possible. This ought to be the case whether it relates to the exceptional quality of that information or whether it relates to its ability to know the essence of a person, or whether it just relates to normal health-care. Along with Friedman Ross, I support the view that not just DNA information but also non-genetic medical information should be protected through the best means possible. I imagine that this is in everyone’s best interest.

In addition, besides the arguments raised by Friedman Ross against treating genetic information as exceptional, Margaret Everett also highlights the trap of thinking that genetic information is somehow special—exceptional if you will. According to Everett,

\begin{quote}
Treating genetic information as special or “exceptional” may well lead to the trap of having to provide greater restrictions on its use and dissemination. The dilemma is that the perception that DNA is exceptionally powerful information increases the risks of discrimination and stigma.\textsuperscript{481}
\end{quote}

On Everett’s view, it appears that even if genetic information is exceptional, it would be better to treat it as unexceptional and the same as other medical information, because treating this information as exceptional could increase the risks of discrimination and stigmatization.

\textsuperscript{478} Better Health Channel, 2011(b), p. 2.
\textsuperscript{479} Friedman Ross, Lainie 2001, p. 143.
\textsuperscript{480} Ibid., p. 145.
\textsuperscript{481} Everett, Margaret, 2004, p. 287.
Since we are seeking to address the best interests of the child, problems of discrimination and stigmatisation should be avoided, where possible. If this means treating genetic information as unexceptional then, on this view, this is the better way to go.

However, Everett is also concerned about restricting the use and dissemination of genetic information because restricting the use and dissemination of genetic information is not always in the best interest of a person. Everett’s view is understandable since there are several instances where our personal information needs to be disclosed to others. For instance, genetic health information may need to be disclosed to a doctor, if one needs medical care and one is suffering or concerned about the possibility of suffering a genetic medical condition. In addition, people sometimes have to disclose their genetic medical information to other medical personnel, dentists, nurses, Centrelink for eligibility for Sickness Benefit and so on. As a result, sometimes people’s medical information is required by a number of different institutions, including hospitals, doctors, clinics and Medicare, to name but a few. We take this risk with our privacy because of some greater good we hope to gain, such as better health. Clearly there are instances when we would not want to restrict the use and dissemination of our medical information even when this poses risks to our privacy.

If Friedman Ross and Everett are right, then the information extracted from the DNA samples used to identify the genetic parents of children ought not to be considered different or special in comparison to other medical information. Indeed, considering it different or special could lead to discrimination and stigmatisation. So, the argument that collecting genetic information could produce additional risks to children’s privacy is not justified on Friedman Ross’ and Everett’s views.

Furthermore, if Friedman Ross and Everett are right, it would be better if this information is treated to more stringent privacy protection; not because it is distinctly different to other medical information, but because all medical information should be provided with these stringent privacy protections in order to protect people from the risks of discrimination and stigmatisation.

**Discussion About The Privacy Concerns Raised By Collecting DNA Information**

So far, I have discussed the privacy protection norm currently in place in the form of the *Privacy Act 1988* and how my policy could adhere to the privacy principles contained in this Act. Nonetheless, this Act may fail to protect the information I propose is gathered because it is collected in a different way to the information already in the public sphere and the information provided to a family doctor. Through further analysis it became apparent that my
proposal raises concerns for contextual integrity as described by Helen Nissenbaum on three grounds—the information is different to the information that is currently collected; the information is collected in a different way to the current way information is collected for a birth certificate (in some ways the closest similar information that is gathered by government); and the information is capable of producing other sensitive information that could lead to risks for personal privacy. There is a possibility, for instance, that the information gained from the DNA tests for genetic parentage could lead to discrimination and social stigma if ever disclosed to those not authorised to have it. In this sense, there is something distinctive about collecting DNA samples to identify connections between people. DNA testing can provide more information about a person than the information that is currently available to us on a birth certificate, for instance. DNA testing can also provide information about current and potential health problems and it has the ability to make connections between people. These are only some of the capabilities of DNA testing.

Although I do not support the genetic essentialists’ view on the grounds that we are more than our gene, clearly their arguments would support strict measures to protect the privacy of information gathered from DNA. On the other hand, from the genetic exceptionalist’s point of view, the measures to protect DNA information are insufficient because of the ability of DNA to reveal things about us that could lead to discrimination and social stigmatisation. Therefore, on both these views, the information that I propose collecting would need stringent privacy protection measures, but the current measures are insufficient to protect it.

Even if we accept the views of the non-exceptionalist, then we have to agree that although DNA information is not exceptional, it ought to be treated to the most stringent privacy protection that is currently possible to provide, not because the information gathered through DNA testing can reveal more about who we are than information gathered about us through typical medical channels, but because all medical information should be treated to the most stringent protection measures available. Treating DNA information as exceptional, however, calls for an increase in privacy protections over that of other medical information.

However, as Friedman Ross points out, there is no reason to think that genetic information is any different to other medical information and her arguments seem to be reasonable, given that much of what she argues, such as ‘disease expression is influenced by other genes and by the environment’ often turns out to be the case—smoking, for instance, also has an impact on our health.

Everett’s argument that ‘the perception that DNA is exceptionally powerful information increases the risks of discrimination and stigmatisation’ fails to convince and raises concerns
about treating genetic information as similar to medical information, when DNA information could be used to gain information about our other genetic family members. If, for instance, there is a chance that children and those DNA tested for genetic parentage are at risk of stigmatisation and discrimination because we treat genetic information as unexceptional, this would not be in children’s best interest nor those that were DNA tested. These distinctions between my proposal and the norm and the capabilities of genetic information to produce probabilistic health information (even if this is not the best predictor of future health) can lead to risks that weigh heavily in favour of more stringent privacy policies. Furthermore, if treating the information as exceptional leads to discrimination and stigmatisation and treating it as unexceptional leads to the same outcome, then it seems to me that we have reached an impasse. However, because DNA has the ability to provide more information about me than that information that could be gained from my medical records; I am inclined to the view that there is something special about genetic information—exceptional if you will.

Furthermore, unlike Everett, I do not advocate easing restrictions on the use and dissemination of the genetic information I propose is collected, but rather I support Friedman Ross’s view of providing greater restrictions on its use and dissemination. These greater restrictions on the use and dissemination of the information I am suggesting is collected are necessary in order to comply with an important requirement of Nissenbaum’s heuristic, which highlights the number of ways that my proposal is importantly different from the current norms that are in place when collecting information about people.

Nonetheless, despite their disagreements of the exceptional nature of DNA, the exceptionalist (Annas) and the non-exceptionalist (Friedman Ross) along with the essentialists would have to agree that it is better to treat the genetic information I call on be collected to the most stringent privacy protections that it is possible to provide, not on the grounds that it is DNA information, but because all medically related information should be treated this way. What seems to come through from the above discussion is that despite the privacy protection measures that are currently in place, there is clearly a need to treat the DNA information and all medical information to stringent data protection measures. Furthermore, those privacy measures currently in use seem to be insufficient.

**Conclusion**

In conclusion, my policy proposal could comply with the current privacy principles that govern the collection of personal information. Furthermore, by not retaining information about those not genetically related to a child, we can reduce the risk of privacy breaches for
those persons. This would reduce the number of persons at risk of privacy breaches following
the adoption of my proposal.

Where it cannot comply fully with the principles of privacy, such as sole access to
information, this should not be problematic, because it is in the child’s interests that her
social and genetic parents have access to this information also.

However, a number of distinctions were noted between my proposal and the information
collected under the current norms of privacy protection. These distinctions raise concerns
about the need for more stringent privacy protections, which raised discussion on the
essential and exceptional nature of genetic information.

While there is an argument for genetic exceptionalism, I dismissed the view that we are
essentially our genetic material on the grounds that we could be shown to be otherwise. On
the other hand, it was accepted that DNA has certain abilities, which general medical
information does not. I, therefore, conclude that genetic information is somehow special and
worthy of the most stringent protection. This may help alleviate some privacy concerns.
However, as many of the problems associated with collecting DNA information relate to the
data protection measures surrounding that information in a database, I take up this discussion
next.
Privacy Protection And Data Integrity, Part 2

There may be some concerns that storing DNA information, in addition to collecting it, could be a potential risk to peoples’ privacy. If mandatory DNA testing of newborn children to establish the identities of their genetic parents were to be instituted into Australian law, it would require setting up a DNA database to contain the information. This database would contain the profiles of those who were DNA tested—the newborn children and their genetic parents. However, it is generally accepted that databases can be a source of privacy risk: they can be breached, and information that was gathered by one agency for one purpose could be used by another agency for another purpose. Indeed, according to an online news report for the Mail, a breach has already occurred to one overseas government DNA database. As a result of the risks that attach to databases containing people’s private information, there may be concerns about storing information about genetic parentage in one. Indeed, it could be claimed that even government databases cannot be entrusted with this type of information about people.

The paediatricians Robert Williamson and Rony Duncan argue in relation to DNA testing of newborns, “If the correct safeguards are in place to protect civil liberties, why should a proposal to test everyone at birth be a frightening one? On the other hand, if the correct safeguards are not in place, and the fears are justified, why are we daring to test anyone at all?” In addition, Van den Hoven’s argues that “In an information society, there is a new vulnerability to harm done on the basis of personal data-theft, identity fraud, or straightforward harm on the basis of identity information.” According to Van den Hoven, “In information societies, identity-relevant information resembles guns and ammunition.” This is in so far as “Protecting identifying information, instead of leaving it in the open, diminishes epistemic freedom of all to know, but also diminishes the likelihood that some will come to harm, analogous to the way in which restricting access to firearms diminishes both freedom and the likelihood that people will get shot in the street.” Therefore, according to Van den Hoven, “Preventing information-based harm clearly provides us with a strong moral reason to limit the access to personal data.”

---

482 Gallagher, Ian & Myall, Steve, 31/03/2007, np.
483 Ibid.
485 Ibid.
486 Ibid.
487 Ibid.
In this chapter, I look at the possible privacy risks that may arise when storing DNA profiles of children and their genetic parents in a database and the sort of privacy protections that could be instituted to prevent or limit access to it.

**Distinction Between Databases And Biobanks**

When seeking to store personal information in a database, one of the initial things that needs to take place is to distinguish between the available systems in order to select the most appropriate one for the storage of the data. Sometimes DNA information is held in a database and sometimes it is held in a biobank. It should be noted that there is a major distinction between a database and a biobank. For instance, a database stores, manages and allows for the retrieval of information. To identify individuals through genetic testing, scientists scan 13 DNA regions, or loci, that vary from person to person and use the data to create a DNA profile of that individual (sometimes called a DNA fingerprint). This profile would be stored in a DNA database. This profile can then be cross-referenced with other profiles in the database to gain a positive match between individuals.

A biobank, on the other hand, contains the genetic material itself. According to the National Health and Medical Research Council “a biobank is generally a large collection of human biological materials (biospecimens) linked to relevant personal and health information and held specifically for use in health and medical research.” In addition, “The aim of biobanks is to facilitate health and medical research, particularly that which is multi-centre and multi-national, while appropriately protecting participants’ interests and privacy.” Although the samples from DNA testing for parentage could be stored in a biobank, my main focus is on the collection and storage of genetic parentage information rather than on the collection and storage of genetic material. Furthermore, the physical material held by a biobank cannot be encrypted in the same way simple data can. Therefore, information held by a biobank may be used more easily to identify people and to draw conclusion about their health status, for instance. Therefore, my focus is on databases rather than biobanks. This, of course, is one advantage to my paradigm shift proposal because the storage of DNA information in a database is less of a privacy risk to individuals’ personal information than the storage of DNA samples in a biobank. However, despite this advantage to my proposal,

---

489 National Health and Medical Research Council, 2010, p. 4.
490 Ibid.
the collection of DNA information about people may still raise privacy concerns regarding their data protection.

**Some Concerns Regarding Storage Of DNA Information**

Given that certain information about people needs to be collected and stored, such as health information, taxation information and information for Centrelink when one is a recipient of a government benefit, it is essential that private information remains just that—private. According to a report by the Australian Law Reform Commission (ALRC) conducted during 2007 and 2008, “The overwhelming message arising from ALRC consultations was that Australians do care about privacy, and want a simple, workable system that provides effective solutions and protections.”

In addition, a recent survey carried out by the Human Genetics Commission on behalf of the British government suggests that most people in the UK are generally in favour of genetic testing for various reasons, provided this process is not abused.492 According to this survey,

The public support the use of human genetic information to improve the diagnosis of diseases, to develop targeted drugs, and to better understand people’s susceptibility to certain diseases. 94% think it should be used to identify or eliminate possible offenders from Police enquiries, and four in five supports its use to establish paternity, or other family relationships.

If the Human Genetics Commission survey is reliable, then it is clear that the majority of people (80% or 4 in 5) in the UK support the use of DNA testing to identify parentage and family relationships. I have no reason to doubt that Australian citizens feel much the same way, given the evident universal interest in knowing who one’s genetic relatives are.

However, UK citizens in this survey who, while supporting DNA testing, also supported “stringent regulations on access.” This appears to be in line with the views of Australian citizens. If data protection is stringent and access limited to those with a legal right to the information in the database, then there is no reason why a DNA database containing information about genetic parentage should not be established for the benefit of Australian children and as a means of fulfilling their right under Article 7 of the CRC.

493 Ibid.
494 Ibid., np.
**Those With An Interest In The Information**

As there may be an interest in information that is collected via DNA testing, data protection problems can arise because, as discussed earlier, DNA data contains personal information about a person’s susceptibility to genetic medical problems, information that individuals may not want others to know. The fears are that this sort of information could be used, without the individual’s consent, for things like genetic research, to raise insurance premiums, to prevent them from gaining employment, or to draw certain inferences about them through data-mining. People are concerned that if others have access to their genetic information, then they will simply know too much about them.\(^{495}\) (Here we note again the inferences to genetic exceptionalism and essentialism).

Thus, there is the additional concern that storing personal information in a database and making it available to one organisation could lead to its disclosure to other individuals or organisations, without the consent of the persons whose information it is. Thus the concern here is that if this information were collected to identify genetic parents of children, then it could be disclosed to other organisations, which could use it for purposes other than that for which it was originally collected.

**Privacy Concerns Regarding Employment Prospects**

Another reason for thinking that it is better to curtail the information to just what is required to identify the genetic parents of a child is that if more than this information is retained, the additional information (or DNA sample, if that was retained, not something I advocate) has the potential to lead to greater interest in the information. For instance, it is sometimes feared that should employers be able to access genetic information about employees or potential employees that job prospects would be put in jeopardy for those who are at risk of inheriting a genetic health problem. This is one reason for thinking that the information held in the genetic parentage database should be restricted to the information that is required to satisfy the requirements of Article 7 of the CRC and that this information should be strictly and forcefully protected. Discrimination on the basis of a potential risk of disease is deeply problematic and would obviously be a concern for those DNA tested.

However, fears that employers would gain access to parentage information following my proposed paradigm shift are not fully justified because I am not advocating the retention of DNA samples or information other than the names of genetic parents and their children. It is

\(^{495}\) Ibid., p. 5.
my personal experience that employers are not generally concerned about potential employee’s genetic connections to their family members. They are more often concerned about employing the person with the best qualifications for the position, which has little to do with the identities of one’s genetic parents. Furthermore, a potential employee’s genetic parentage is information an employer could straight out ask the potential employee at the job interview. Therefore, it seems to me that if there was no information in the database other than the identities of genetic parents and their children (information, I claim is valueless to potential employers), that this would prove enough of a disincentive to potential employers to want to seek this information from a genetic parentage database.

Regarding the argument that an employer would be interested in gaining access to information about a potential employee’s medical status, as most people are aware, many businesses these days insist on a medical examination prior to providing employment to potential staff. Indeed, a medical examination is usually a prerequisite for government employment in Australia and in many other countries. One may need to answer a number of medical questions prior to working in the mines in Australia, for example. According to one mining company for instance, a “pre-employment Medical consists of questions that determine the candidate’s medical condition and fitness to undertake the duties of the role.”

To be eligible for employment in this Australian mining industry one is required to answer questions in relation to:

- lifestyle;
- physical condition;
- personal health history; and
- blood pressure/heart rate.

As can be seen from this list, personal health history is requested in these medical examinations and not all relate to genetic medical conditions—one’s physical condition could be a result of lifestyle choices. Employers can and do request and obtain medical information about their employees and potential employees without the need to seek it from a database that should only contain the information I call for. While the benefits of gaining health information about a potential employee are obvious, there is no clear evidence to suggest that employers are obtaining information about potential employees in that way. Rather, there is clear evidence that employers are gaining information about potential employees’ health

496 Mining People International, 2011, np.
497 Ibid.
through pre-employment medicals. Therefore, I am not convinced that there is a threat to people’s future employment prospects through storing the information that I propose is stored in a database. However, if there was, then this is reason to step up data protection measures, not deprive children of their right as stipulated in Article 7 of the CRC.

By insisting that only the information about the genetic connectedness between parents and their children is retained, this would further help to reduce the risk to people’s personal information, because it would reduce the amount of information that is collected and stored on them. In addition, keeping the information in a separate database to the information on birth certificates, for instance, would also help to reduce risks, because a birth certificate holds more information than I am proposing is collected. Information on a birth certificate can amount to parents’ names, children’s names, date and place of the child’s birth and sometimes sibling’s names, for instance. This additional information on a birth certificate identifies people with a particular place and time, which could lead to easier identification. Furthermore, as there is more information on a birth certificate than I am proposing is provided on the ‘genetic parentage certificate’, would this not provide greater incentive for others than those with a right to the information to try to access the database containing the information on birth certificates instead? By providing only the identities of genetic parents and their children, we reduce the risk of data integrity and other unlawful uses the data could be put to without the consent of the genetic parents and their children. This reduces the risk to their data.

**Privacy Concerns Regarding Insurance Cover**

However, it is also sometimes claimed that besides employers, insurance providers are a potential risk when it comes to storing DNA information in a database. So, for instance, a more informed public may respond differently to providing DNA information if it was disclosed to insurance companies and they were rejected for insurance cover or their premiums were raised. However, there are other ways that an insurer could get medical information about a person, if they were desperate enough, besides obtaining it illegally through breaching a private DNA database or gaining it without a person’s consent. Not that I am advocating that insurance companies should do so, but for the desperate insurer, DNA is readily available to others when we shed hairs or leave fingerprints on doorknobs or saliva on a drinking glass. Shaking hands with a person could lead to your DNA being transmitted to his hands and his to yours. Furthermore, we shed skin as we go about our daily lives—skin also contains DNA. Indeed, there are numerous ways to obtain a person’s DNA without
having to obtain it from a private, what should be heavily protected, database. Again, the easiest way to get information about a person’s family medical history is to ask them for it or to obtain it via a medical examination, as is the case for employers. However, it should be remembered that my proposal only calls for the retention of information identifying the connections between genetic parentage and their children, no other information from those tested should be retained and the DNA samples should be destroy following testing.

Of course, the most obvious solution to protecting information in a database is to institute stringent laws to protect it from becoming available to employers or insurers and to make the breaches of DNA databases a very unattractive process for would-be infiltrators of electronic data. Of course, if there is a breach to a database, this means that the data protection measures in place for that database need to be upgraded.

**Privacy Concerns Regarding Research**

Research is another area of concern for people’s privacy when collecting DNA information. The Icelandic company deCODE Genetics was established in part to conduct scientific research on the Icelandic peoples’ genomes in an effort to produce better medical treatments for Icelandic citizens.498 Despite the fact that the Icelandic people voluntarily contributed to the DNA database, there is some concern that companies with DNA databases, such as deCODE, could sell DNA information to other companies without consent, for supposedly ‘research’ purposes. This could result in DNA information being used in research to draw conclusions about the ethnicity of people and their potential for particular conditions, such as sickle cell anaemia, for instance. This condition is most common in people of a particular ancestry. Were this information to fall into the wrong hands it could lead to discrimination or stigmatization of certain groups of people.

**Privacy Concerns Regarding Agents**

In addition to only maintaining a limited amount of information following identification of genetic parents of a child, an agent who is tasked with providing this information to the relevant recipients should be bound by privacy laws in order to prevent them from discussing the information they have access to with others. This is mandated in many government jobs and, indeed, in most places where people have access to personal or sensitive information, including hospital staff, who must keep patient information private from those who have no

498 deCODE Genetics, 2010, np.
right to it. It is, of course, understood that all these agents would be bound by a strict information privacy code, as is currently the case with other personal information retained by governments and medical institutions and practices. If Van den Hoven is correct then “In the design of a hospital information system for example, difficult privacy issues may be resolved by deciding in which situation which professionals can do what to which types of information. Information maps are thus drawn up and ‘privacy issues’ are addressed in detail.” These types of data protection measures help address some of the privacy concerns regarding those legitimate persons who need to access the information, such as the processors of the data and the agents who are tasked with disseminating the information to the recipients.

**Privacy Concerns Regarding Data-Mining**

Another problem with storing information in a database is that by doing so we make it susceptible to use, not by the people charged to collect and convey the information, but by governments and others using the information for other purposes. In the words of Van den Hoven, “What is often seen as a violation of privacy is often more adequately construed as the morally inappropriate transfer of personal data across the boundaries of what we intuitively think of as separate ‘spheres of justice’ or ‘spheres of access’.” The concern when this occurs is that the information that was collected in one ‘sphere’ could be combined with other information from another sphere and the resulting information could be used to draw conclusions about persons. This could be achieved by combining the information about genetic parentage, for instance, with information from another database/s to draw conclusions about people. They may do this in order to gain more knowledge about people—knowledge discovery from combining data from different sources. This process is known as data-mining. Data-mining, or knowledge discovery in data (KDD), raises concerns because it utilises “large data aggregations to draw inferences about individuals.” If information is used in this way, it could lead to the identification of those whose information is contained in the databases. This is problematic if we are seeking to protect the identities of genetic parents and children from those with no entitlement to their information. A simple example of this problem is presented by Ljiljana Brankovic and Vladimir Estivill-Castro in their paper *Privacy Issues In Knowledge Discovery And Data Mining*. They present the following scenario where we are asked to consider a data set where:

---

500 Ibid., p. 314.
501 Nissenbaum, Helen, 2010, p. 44.
there are 10 people, 2 females and 8 males,

- there are 8 cases of disease A,
- none of the females has disease A.

If it is known that Mr. X’s information is part of the data, it is possible to infer that Mr. X has disease A. While the number of persons in this scenario is small compared to the number of persons that would be included in the database I propose, and therefore, it would be easier to identify individuals in this scenario, the possibility that data-mining could lead to identification of individuals poses a major concern for my proposal, even if the information is stored as unidentifiable information.

Another problem with data-mining is that when combining information from different databases, inferences can be drawn leading to stereotyping of persons. This is problematic because, according to Van den Hoven, “We want to be able to present ourselves and be identified as the ones we identify with. Stereotyping is an extreme case of casting people and pre-empting their choice to present themselves.” Clearly, concerns regarding data protection from data-mining need to be fully addressed before any DNA information is stored in a database, government-controlled or otherwise, genetic parentage information or otherwise.

**Britain’s Criminal DNA Database**

As is well known, DNA testing is currently carried out for a number of reasons, most notably for detecting criminal suspects. According to a BBC news report, the DNA of every person suspected of a criminal offence in Britain is held in the National DNA Database (NDNAD). Although intended as a criminal database, NDNAD also contains the DNA of innocent people, as previously discussed, including an estimated 585,000 samples from children under 16 years of age. This database is effective in a number of ways at detecting criminals and is a good model for discussing one of the problems with storing information in databases (given it is the largest in the world per capita and under constant scrutiny). The NDNAD has drawn a lot of criticism, mainly concerned with the retention of the profiles of those found innocent of a crime, as previously discussed. However, another problem with the NDNAD is that it was breached.

Indeed, in early 2007, five civil servants were arrested on charges of industrial espionage for allegedly stealing DNA information from the UK Government’s Forensic Science Service.

504 University of Leicester, 2010, np.
database (NDNAD) and using it to establish a rival firm. Consequently, people have a right to be concerned about data protection measures when it comes to DNA databases, because these technological devices, although wonderful in many ways, are no idle threat to personal privacy. While the information that was stolen from NDNAD was not disclosed to others, and, therefore, did not actually breach individual privacy rights as such, there could well have been a major breach of citizen’s privacy. Therein lies another cause for concern when storing DNA information in a database. The breach of NDNAD shows that it is possible to breach the data protection measures of even a government database, which one would assume had the very best data protection measures in place.

This is further reason for thinking that, even if there was nothing exceptional about DNA information compared to other medical information, all things considered, it would be better to treat it as though it were when it comes to storing it in a database. A database containing DNA parentage profiles, although it may not need to be as highly secured as the NDNAD, since it would only contain the names of genetic parents and their children, still needs to be stringently protected. Clearly, the database containing the information I propose is collected needs to be better protected against breaches than the NDNAD. Thus, I strongly recommend that data protection measures need to include a provision against breaches by rival operators. Naturally, I recommend this provision for all private personal data.

**Concerns Data Protections Measures Are Not Keeping Up With Technology**

Currently, medical information that is held by a family doctor or hospital is protected by the *Privacy Act 1988*, which the government mandates. Many would think that this was data protection enough. However, as has already been shown, retaining information in a database, even a government agency, can be a source of risk to the personal information contained in it and thus there is a risk to the privacy of the individuals whose information it is. A Human Genetic Commission survey notes that seven in ten people have little or no confidence that the rules and regulations are keeping pace with new research developments. As the system I propose setting up is new and may require innovative data protection measures in order to keep pace with emerging technologies, this is problematic, because if the database infiltrators are more technically advanced than the systems designers, then the system would be at risk of breaches.

---

505 Gallagher, Ian & Myall, Steve, 31/03/2007, np.
Thus, it is vital that the information I suggest is gathered be treated to the most stringent privacy protections as possible. The Privacy Act 1988 in and of itself may not provide sufficient data protection measures for the information that is stored in existing DNA databases and, therefore, may not be sufficient for the one I am proposing. While there is no evidence to suggest that there have been data protection breaches to Australian DNA databases similar to the breach of the UK NDNAD, this does not mean that this cannot happen in the future when new information is gathered or is gathered in a different way to the norm. So, assuming that the database I propose is ever established, the question becomes how is it possible to protect it against infiltration and data-mining?

**Encrypting Information**

Naturally, there are a number of measures that could be instituted to protect the information I call on to be stored in a database. For instance, for data protection reasons, DNA profiles are generally encrypted when stored in a computer database, making the information difficult, though not impossible, to access. A DNA profile from the UK criminal database (NDNAD) would look something like this when encrypted: 15,18; 6,9; 11,13; 22,22; 31,32.2; 14,17; 17,20; 11,132; 13,16.3; 15,16; XY.\(^{508}\) Evidently, there is very little to identify the person and his or her private information from this encrypted profile. There is nothing, for instance, that a layperson, not versed in DNA-profile language, would gain from accessing this encrypted DNA profile. This would be true even for a person accessing her own profile. However, the people seeking to obtain information may well find ways to decode the information. Encrypting information, therefore, may only ensure that this information is not easily understood by the average layperson.

Of course, even if encrypted, at some point the information will need to be decoded in order to produce information that is accessible to children and their parents—providing encrypted information to them would not be in keeping with Article 7 of the CRC, since unless children and their parents were versed in the encryption code, they still would not have the information in the true spirit of what the fulfilment of Article 7 means. So, at the point of disclosure of the information to the child and/or her parents, the information has to be decoded. Thus information would only be unidentifiable while it was encrypted. Encrypting information beyond the capabilities of the agent who has to convey the information to the recipient is clearly not feasible. So, while encrypting information in a database is one of the

\(^{508}\) National Policing Improvement Agency, 2010, np.
first measures that ought to be instituted in order to protect information in a database, it clearly has to be decoded at some point for the benefit of others besides the recipients, such as those who input the information into the database and those who extract it in order to provide it to the recipients. This is problematic, because if the information becomes decoded at some stage, this means that others could gain access to it—those providing the information to the child, for instance. However, as previously stated, these persons should be under a strict code of secrecy, as would generally be the case for hospital staff and government agents.

Encryption should be seen as only one of the measures that are applied to the information I am proposing is collected. For even if it cannot fully protect the information from others than those entitled to have it, encryption of personal data is a safer data protection measure than not encrypting data at all. While encryption cannot provide full protection of data in a database against breaches, especially following decoding, this simple measure allows people to retain a certain amount of control over who can access it. However, it is noted that this is seen as a weak method of data protection.

Some Other Solutions To Protecting Personal Privacy

Data protection standards for DNA databases and, indeed, the data protection measures of any private information contained in a database must keep up with technological advances and the abilities of others to infiltrate the data in databases. Where this does not occur, data protection measures should be improved to keep pace with the changing and driving pace of technology and hackers. The right to privacy of personal information in a database should not be compromised by failure to provide the correct data protection measures for private information.

Furthermore, it is not enough for system designers to keep pace with technological advances; they must seek to always anticipate what problems could arise in the future and then seek to solve them before personal privacy is jeopardised.

In addition, NDNAD was breached by a rival company hoping to set up a DNA database in opposition to the government-run one. There is a problem with the system if a company can infiltrate a database. There is another problem if a company is allowed to set itself up in opposition to a government run database. There is particular concern if a company is permitted to set itself up in opposition to the database I propose is instituted. One reason for thinking this is problematic is that it would allow more people access to the information. The less people that have access to personal information, the more we move closer to protecting
that information, thus to protecting people’s privacy through the protection of their personal data.

In addition, if a company resorted to infiltrating a database that contained personal information about individuals, then they could not be trusted to protect that information. This is because that company would have already shown itself to be unscrupulous by infiltrating the database in the first place. Such unscrupulous individuals or companies could sell this information on to others, thereby disseminating the information among a greater number of individuals, maybe even many others. This, of course, is a major concern. As a result, I propose that such unscrupulous behaviour be made illegal, because it has the potential for risks to people’s personal privacy, perhaps on an unprecedented scale. This is why the setting up of a database in opposition to the one I propose should be made illegal. Only one agency ought to be permitted to control the flow of the information I propose collecting (as is the case with the control of the flow of information on birth certificate).

Furthermore, there should be heavy penalties instituted for any breaches to the database and for providing the information I propose is collected to others not entitled to have it. If a company could not legally set itself up in opposition to the government’s or government controlled agency’s database, and any breaches were considered espionage and illegal, this would go some way to ensuring that any attempts at breaching the genetic parentage database would be treated as a criminal offence. If strong data protection measures were instituted and enforced and heavy penalties put in place for breaches and disclosure, this would further help reduce the chances of a breach to the genetic parentage database.

Of course this does not address those, such as government itself from data-mining information from the database. This sort of privacy breach calls for measures whereby information that was collected for the purposes of genetic parentage identification is not used for other purposes, including data-mining by the government without the informed consent of the individuals whose information it is. This is in keeping with respect for people’s autonomy and rights regarding their personal information as advocated by Van den Hoven. Van den Hoven argues for the justification of a “potent regime of individual rights which constrains access to information about individuals” on four grounds, including harms, discrimination, equality and fairness and respect for moral autonomy. Taking moral autonomy, for instance, Van den Hoven argues that

---

510 Ibid.
The conception of the person as being morally autonomous, as being the author and experimentator of his or her own moral career, provides a justification for constraining others in their attempts to engineer and directly or indirectly shape the subject’s identity, either by stereotyping, or by the application of identity-management tools and techniques. Data-protection laws thus justifiably provide protection against the fixation of one’s moral identity by others. They do so by requiring informed consent for the processing of identity-relevant information. If there are domains where for obvious reasons individuals in well-ordered societies cannot be allowed to write their own biographies from cover to cover, they at least should be allowed to write those parts that are amenable to it and individuals should be given an opportunity to authorize the parts that were, or had to be, written by others.511

Van den Hoven provides a second reason in respect of moral autonomy, which he refers to as knowledge by description.512 He argues,

Factual knowledge of another person is always knowledge by description. The person himself, however, does not only know the facts of his biography, but he is the only person who is acquainted with the associated thought, desires, emotions, and aspirations. However detailed and elaborate our files and profiles on a particular individual may be we are never able to refer to the data subject as he himself is able to do. We may only approximate his knowledge and self-understanding.

By ensuring that information about the genetic parentage of children is not available for use by government and non-government agencies for purposes other than that for which it was gathered, namely, to provide information to children about the identities of their genetic parents (which is intended, it is argued in this thesis, to add to the facts of his narrative identity or ‘biography’ in the words of Van den Hoven), this should further reduce concerns about gathering and storing this information in a database.

If the genetic information I propose collecting is held in a DNA database as encrypted information until it is required by the recipient and if stringent data protection measures are instituted and forcefully applied and if access is limited to only those with a legal right to the information, then principle (g) of the IPPs will be addressed, along with all the other IPPs. Furthermore, it will satisfy Nissenbaum’s criteria for contextual integrity and Van den Hoven’s and Friedman Ross’ calls for more stringent privacy protection and for constraints on the flow of information. Once problems of data protection and data integrity have been addressed, there is no reason why a DNA database to identify the genetic parents of children should not be established in order to fulfil children’s right as expressed in Article 7 of the CRC.

511 Ibid., p. 317-318.
512 Ibid., p. 318.
Conclusion

In conclusion, clearly, data protection measure surrounding the storing of DNA information in a database is a source of concern. However, the genetic parentage database I call for should only contain the names of genetic parents and their children. This reduces the risks to privacy when storing genetic parentage information electronically in this technological age. Furthermore, if the names of a child and her genetic parents is properly encrypted and non-identifiable until requested by them; is strictly and stringently protected with strict measures of protection in force; and if the information is available only to the individual or individuals who have a right to it, such as the children and their social parents; and if that information is not made available to others without their informed consent; and if every attempt is made to ensure data integrity measures keep pace with technological advances into the future; and if we seek to foresee difficulties that might arise in protecting the identities of those DNA parentage tested, then I conclude that this information should be collected and stored in a database on behalf of children so that they can access this information should they so choose.

Since mandatory DNA testing may be the only means of identifying genetic parents of children, then it is necessary to store that information in a database so that children can assess it at some point. Provided the Australian parentage DNA database was afforded the most stringent data protection that it is possible to provide, then there should be no reason for concern about the privacy of people who are mandatorily DNA tested for genetic parentage. If there are no privacy issues arising from my proposed paradigm shift and data integrity is continually maintained for the duration that the information is retained, then there is no reason why my policy proposal cannot be adopted in order that children may be able to know the identities of their genetic parents. After all, they can have rights on the Interest Theory account of rights and Article 7 of the CRC provides them with this particular right, a right which the government are obligated to fulfil on the grounds of respecting those agreements they sign on to, and in order to avoid harms and to ensure that no child is lacking in goods to which other of their peers have access. After all, this is information that children have shown an interest in obtaining for a number of very important reasons.
Conclusion

When we seek an account of our moral obligations towards children the Will Theory is unhelpful in relation to small children because it cannot account for all obligations in terms of rights. As the Will Theory cannot provide an account of children’s rights, I have adopted the Interest Theory of Rights as my understanding of the nature and foundation of rights, because, in contrast to the Will Theory, the Interest Theory construes moral obligations towards children in terms of children having rights grounded on their important interests. Therefore, if children have rights, it is the Interest Theory account of rights that recognise this. Consequently, I have accepted the Interest Theory account of rights without much discussion.

The CRC, which was developed specifically for children, states the child as the right-holder. However, while unclear on this point, addressees of their rights could include the state, genetic and social parents. Although the CRC is ambiguous in places, a handbook is available to assist with understanding its articles of rights. Article 7 of the CRC establishes that children have a right to know all their parents, including genetic parents. The CRC is the most appropriate means of addressing children interests in the form of rights. I have arrived at this conclusion by comparing other rights treaties that were in force prior to the introduction of the CRC. These treaties, such as the Universal Declaration of Human Right and the Declaration of the Rights of the Child, were shown to be unsuitable for children and lacking in many of the rights that we normally take for granted, such as the right to life and the right to an education.

It was considered that if children are never informed that they are adoptees and donor-conceived children that there is a risk of them not being informed of their genetic family health history. This was thought problematic because it could lead to them being unaware that they could suffer from genetic health problems, thereby failing to take steps to rectify health problems. Methods of discovering health problems through gene sequencing are currently unusable by the medical profession or the general public. And, although this may change, the costs incurred in determining health this way were considered prohibitive for most people and the results unreliable. While stem-cell therapy offers hope of healing ourselves, this advancement is not yet at the stage where it can heal us without the assistance of organ and tissue donors.

It was also considered that adoptees and donor-conceived persons who are never informed of their adoptee and donor-conceived status were at risk of forming consanguine
relationships with their genetic parents, siblings and half-siblings. Without factual information about their genetic parents, children run the risk of having reduced autonomy in adulthood. It is these risks that the right in Article 7 of the CRC seeks to avoid.

It was, therefore, concluded that the easiest and most inexpensive way to find out what a child’s predispositions to genetic illnesses are is to find out what health problems have developed in her genetic family. Health information gained from one’s genetic parents is generally more readily available, more cost effective and more reliable, leading to better health and greater autonomy when making informed health choices. However, although beneficial for children to have and to which they would have natural access if they were reared by their genetic parents; I do not call on this information to be obtained from the mandatory DNA tests that I propose. Rather, it is thought that genetic parents would provide it to their children themselves on beneficent grounds in the best interest of their children.

It was also noted that many children have a strong desire to know the identities of their genetic parents and that some of them are actively seeking out this information. It was concluded following the reports by the NSW Law Reform Commission and the Willis Report that children want to know the identities of their genetic parents and were actively seeking this information out even under the paradigms of closed adoption and anonymous gamete donations, which led to changes in the law and the Adoption Information Act. I focused on reasons that were addressed for denying children information about their genetic parents including reasons for instituting closed adoptions and concluded that they could no longer be justified in today’s society. It was thought that open adoption brings closer to realisation the right contained in Article 7 of the CRC for adoptees. It was recognised that information is not available on all genetic parents for disclosure to their children, which is especially true of overseas adoptions. Nonetheless, it was concluded that open adoption may alleviate or eliminate some of the possible risks that adoptees born in Australia may encounter through lack of information about their genetic parents.

Furthermore, it is thought that Velleman is correct to argue that it is unfair and immoral to deny children information about their genetic parents since it impacts their self-knowledge and their sense of identity. It was also considered that, because it can impact their sense of identity, it would be better if information about genetic parents was given to children early in their lives so that they can more easily assimilate it into their accounts of themselves. It was thought that this would aid in the formation and consistency of their narrative identity over time. While it may be considered more appropriate to only provide this information to children when they acquire decisional capacity, the problem with this approach is that it
could lead to children suffering genealogical bewilderment. It was concluded that this harm could be avoided by providing information to children early in life. The benefits and avoidance of risks that result from knowing something about one’s genetic parents are sufficiently important concerns to justify rights protection.

However, there may be some instances where it may be necessary to withhold this information from children for long periods of time. Family break-ups, incest, rape, abuse and the risk of murder are situations that call into question the importance of avoiding psychological problems such as genealogical bewilderment when a child may encounter more serious problems if she is told. While one option may be to only provide children with this information when they are older, violent risks to some mothers and children may require that this information is only provided later in life or only with the mother’s consent or never provided to those children whose father poses an on-going threat.

As with adoptees, the reasons for formerly withholding genetic family information from donor-conceived children are no longer accepted as relevant either and some states have already moved to ban this practice and the other states are covered by rules and regulations that also ban anonymous gamete donations. This is in line with Article 7 of the CRC. I considered arguments presented by parents against providing information to children. However, these were not sufficiently weighty enough to trump their children’s rights to this information. Indeed, if there were any advantages to parents of withholding the information about their children’s genetic parents, it was thought that these could only be slight in contemporary Australian culture. Where advantages to the genetic and social parents of withholding this information from their adopted and donor-conceived children were found to be only slight, it was concluded that there was no justification for supporting their rights to withhold the information over that of their children to have it.

However, it was not only adoptees and donor-conceived children that were considered to have a right to information about their genetic parents; children whose fathers or mothers are falsely identified were also considered to have this right. These cases pose a greater challenge regarding children’s rights to information about genetic parents. As it is generally considered that the family is the best environment in which to rear children, it was thought that providing children, whose fathers have been misidentified or falsely identified, with this information could result in their family breaking-up while they are still young and vulnerable. However, it was also thought that withholding this information from a child until she is older involves some risk to her health, autonomy, identity and so on and could result in her suffering psychological problems. However, because family are considered so important to children, it
was concluded that in some cases this was an acceptable risk, at least until the child reaches 18 years of age or independency prior to that.

As children are being denied this information and therefore, are at certain risks, it is my conclusion that a paradigm shift is called for in order to ensure that children can realise their right to the information called for by Article 7 of the CRC. The introduction of mandatory DNA testing of newborns and their alleged genetic parents to address the problem of children’s accessibility to information about their genetic parents is, in my view, the only viable option to ensure the fulfilment of the children’s right articulated in Article 7 of the CRC.

One concern with my proposed policy shift is that it could affect people’s right to privacy, including that of children. Unfortunately, the fear of risks to people’s privacy following DNA testing have been shown to have a basis in fact. Even if the collecting and storing of DNA information in a database can satisfy the current privacy principles that apply to personal information, there is still concern that the information could be used for purposes other than that for which it was originally collected. While a number of persons may need access to the information in the database, including social and genetic parents, for instance, there is a concern that others not entitled to have the information may gain access to it. This raises concerns about stigmatisation and discrimination of people base on their genetic susceptibilities. This led me to discussion on the essential nature of DNA. However, this argument was dismissed due to the impact other things like the environment can have on a person’s wellbeing. On the other hand, it was decided that DNA information was exceptional when compared to other private information. However, others have argued that if we consider it so, that this could lead to stigmatisation and discrimination for those whose information is collected. Others have thought that if we fail to consider this information as exceptional, that this could also lead to stigmatisation and discrimination. As a result of these concerns and calls by Nissenbaum, Van den Hoven and Friedman Ross for more stringent protections, I concluded that my policy proposal should only be instituted if stringent data protective measures were in place. This is to insure the integrity of the information. If DNA information about a child’s connectedness to her genetic parents is strictly protected, then there is no reason why this information should not be collected in order to prevent harms to children and in order that they realise a good that other children reared by their genetic parents realise naturally.

Although the costs of instituting mandatory DNA testing of newborns and their parents would be high, these costs could be recovered through the sale of the certificate containing
the information about genetic parents. Of course, this is not the only option available and I have outlined a number of other ways that could be considered to alleviate costs.

Mandatory DNA testing of newborn children and their parents could reduce or eliminate the need for fathers to secretly carry out DNA tests in order to disestablish paternity. As a result, mandatory DNA testing could solve all disputed paternity cases and finalise them early in the lives of children, thus making life more stable for children long term. Furthermore, if mandatory DNA testing of newborn children and their parents were introduced and continued to include the names of all future children and their parents, it is likely that in as little as fifty years that DNA testing would only need to be carried out on children, as their parents profiles would, by that time, already be in the database.

Following careful analysis of a number of issues relating to a child’s right to know her genetic parents, it is my view that we have good reasons to support mandatory DNA testing for genetic parentage. The number of benefits gained in setting up a system of DNA testing for genetic parentage outweighs the justifications for withholding this information from children.

Under the terms of the UN Convention on the Rights of the Child, which the Australian government has ratified and, therefore, should respect and honour, children have a legal right to know who their genetic parents are. As a result, parents and governments have a duty to establish these rights as facts and to make this information available for children to access should they wish to know. Ultimately, if my proposal of mandatorily DNA testing newborn children and their alleged parents were instituted into law, future children would be able to learn the identities of their genetic parents, which would make Article 7 of the CRC a genuine right and not just a set of guidelines for government and parents to consider.
## Appendix

1. % of population on DNA database | Population | Total persons on DNA database | % of persons on DNA database
--- | --- | --- | ---
Austria | 8,100,000 | 84,379 | 1.04 0.04
Belgium | 10,400,000 | 4,583 | —
Croatia | 4,600,000 | 10,744 | 0.23
Czech Republic | 10,300,000 | 9,098 | 0.09
Denmark | 5,500,000 | 4,084 | 0.07
Estonia | 1,500,000 | 7,414 | 0.49
Finland | 5,200,000 | 32,805 | 0.63
France | 59,300,000 | 119,612 | 0.20
Germany | 82,400,000 | 366,294 | 0.44
Hungary | 10,200,000 | 28,278 | 0.28
Netherlands | 16,100,000 | 14,747 | 0.09
Norway | 4,500,000 | 6,745 | 0.15
Portugal | 10,300,000 | — | —
Slovenia | 2,000,000 | 5,782 | 0.29
Spain | 40,400,000 | 2,656 | 0.01
Sweden | 9,000,000 | 6,115 | 0.07
Switzerland | 7,360,000 | 69,019 | 0.94
United Kingdom | 59,800,000 | 3,130,429 | 5.23
USA | 298,400,000 | 2,941,206 | 0.99
Canada | 32,270,500 | 75,138 | 0.23

Source: Andy Burnham – at the UK Parliament website.
References


Daly, Martin & Wilson, Margo, (1988), *Homicide*, Aldine De Gruyter, New York


Gallagher, Ian & Myall, Steve, (31/03/2007), *Five Civil Servants Suspended Over “DNA Espionage”*, Mail Online, Associated Newspapers Limited, UK


Li, Cao, (01/05/2009), DNA Databank to Trace Kidnapped Kids, Accessed online 29/06/2011, http://chinadigitaltimes.net/2009/05/dna-databank-to-trace-kidnapped-kids/


Macomb County Court, Michigan, (2006), 2006-002342-DP J, Minor vs. Doe, John MSS, transcript purchased from Macomb County Court


Turcotte, Jennifer, (14/10/2010), Cost Of Sequencing the Complete Human Genome, Complete Genomics, via email correspondence on 14/07/2010.


University of Leicester, (2010), Genetics and the Law, Accessed online 30/04/2010, http://www2.le.ac.uk/departments/genetics/vgec/education/under18/topics/law


