

# **A LEGAL ANALYSIS OF “SAVIOUR SIBLINGS” AND “BENEFACTOR CHILDREN” IN SOUTH AFRICA**

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## **SUMMARY**

This contribution aims to explain how the constitutional rights to bodily integrity and autonomy affect, firstly, the legal position of “saviour siblings” and, secondly, “benefactor children”. The article also considers whether parents, in terms of South African law, have the right to make decisions concerning medical treatment and surgical procedures of this nature, on behalf of their children. A number of legal and ethical issues are considered, with the focus being on the legal implications associated with these categories of children being used to save the life of an ill sibling through the donation of tissue or organs. A set of recommendations are advanced so that the legal position may be better regulated.

## **1 INTRODUCTION**

As the Greek philosopher Heraclitus once said, the only constant is change.<sup>1</sup> No more so is this sentiment reflected than in the fields of science and medicine. Research within these fields has led to their constant evolution and advancement.

Possibly, no field of science has changed the world more during the last 50 years than that of genetics. Owing to the accelerating pace of genetic

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<sup>1</sup> The quote used above is a variation to Heraclitus's original quote.

research, there are now considerable and increasing possibilities available to families that have a history of genetic illness.<sup>2</sup> However, some of these possibilities bring with them much concern. One such recent possibility is the creation of one child to save the life of another.

It can be presumed that any parent with a sick child will be prepared to go to any lengths to save that child. This may include the use of genetic and reproductive techniques to create a perfectly matched child to save the life of the sick child – that is, the creation of a "saviour sibling". A "saviour sibling" is a child who was conceived and selected as an embryo by his or her parents, specifically to be an organ or tissue donor for an ill sibling.<sup>3</sup> With the aid of assisted reproductive techniques,<sup>4</sup> scientists are now able to use their knowledge of human Deoxyribonucleic Acid (DNA)<sup>5</sup> and the human genome to screen embryos for diseases and tissue-type them to be an exact match to an ailing sibling.<sup>6</sup>

Not every situation, however, necessitates the creation of a "saviour sibling", as a current sibling may also prove to be a tissue match. A child in this category is referred to as a "benefactor child". A "benefactor child" is defined as a child who was not selected as an embryo and who was not subjected to any scientific procedures, but who is nevertheless a tissue or organ donor for a sick sibling.<sup>7</sup> That a sibling who is not the product of genetic and reproductive techniques can be a compatible match to a sick sibling is relatively slim, with only a one in four chance of there being a match.<sup>8</sup> These slight odds of sibling compatibility, without specifically being

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<sup>2</sup> Foreword by Baroness Helena Kennedy in Human Genetics Commission *Making Babies: Reproductive Decisions and Genetic Technologies Report* (January 2006) 3. See further BBC News "Concern over 'Spare Part' Babies" <http://news.bbc.co.uk/2/hi/health/4663396.stm> (accessed 2011-10-18).

<sup>3</sup> Jacob "Frail Connections: Legal and Psychiatric Knowledge Practices in US Adjudications over Organ Donations by Children and Incompetent Adults" in Freeman (ed) *Children's Health and Children's Rights* (2006) 219 219. A "saviour sibling" has also been defined as "a child selected as a result of genetic screening to have some innate characteristic that will help save the life of an existing brother or sister". Hocking and Ryrstedt "The Perils of Terminology and the 'Saviour Sibling' Dilemma" in Hocking (ed) *The Nexus of Law and Biology: New Ethical Challenges* (2009) 1 2. The term "saviour sibling" is reported as having first appeared in the October 2002 *Journal of Medical Ethics*.

<sup>4</sup> Assisted reproductive techniques include in-vitro fertilisation (IVF).

<sup>5</sup> The scientific definition of DNA is "[a] macromolecule usually consisting of antiparallel polynucleotide chains held together by hydrogen bonds, in which the sugar residues are deoxyribose. The primary carrier of genetic information." Klug and Cummings *Essentials of Genetics* 4ed (2002) G-5. For more information on the topic of DNA see Chapter 10 onwards of the same book.

<sup>6</sup> The double-helix structure of DNA was discovered in 1953 by James Watson and Francis Crick. Exactly 50 years later, and using the structure of DNA as a starting point, scientists have been able to map the entire genetic structure of humans. Alternatively called the human genome.

<sup>7</sup> The term "benefactor child" was created by the authors. This term was created to define the children mentioned above, as the term "saviour sibling" has a very precise meaning and could not be used to include children that already exist and who are used to save the life of a sick sibling. The word "benefactor" was used as it refers to "a person who supports or helps a person". See *Collins Shorter English Dictionary* (1993) 99.

<sup>8</sup> Braude, Pickering, Flinter and Ogilvie "Preimplantation Genetic Diagnosis" 2002 3 *Nature Reviews Genetics* 941 953.

conceived for the purpose of saving a sibling and, the equal scarcity of compatible organ donors, add further support for calls for “saviour siblings”.<sup>9</sup>

Public opinion generally influences the writing of law. In other words, that which is considered as being moral, should be permitted, whereas that which is perceived as unjust and immoral, should be prohibited.<sup>10</sup> In recent years, the matter of “saviour siblings” has become highly controversial and a cause for concern amongst the general population.<sup>11</sup> There are some who have openly expressed their support for this development, while others have expressed their concern.<sup>12</sup> Those who oppose “saviour siblings”, have likened it to scientists and parents “playing God” and maintain that continued advancements in this area will result in society heading down a “slippery slope.”<sup>13</sup> Although public opinion is important, before a decision can be made on the legality of “saviour siblings”,<sup>14</sup> the rights of those involved need to be considered, as “constitutional rights are mutually interrelated and interdependent and form a single constitutional value system.”<sup>15</sup>

The South African Constitution<sup>16</sup> recognizes the right to bodily integrity, which is inclusive of the right to make decisions concerning reproduction.<sup>17</sup> The freedom to make decisions concerning reproduction protects a person’s right to have children or to not have children. This right, it can be argued, is therefore inclusive of any decision to undergo an abortion or to use any technique that will bring about the desired child.<sup>18</sup> In other words, the right to reproductive autonomy can be said to extend to include the decision as to how to conceive a child and for what reason.<sup>19</sup> “Benefactor children”, on the

<sup>9</sup> There are at least 3500 people in South Africa waiting for an organ transplant. See the organ-donor foundation website at <http://www.odf.org.za/> (accessed 2011-11-06).

<sup>10</sup> Swanepoel “A Proposed Legislative Framework for the Regulation of Aspects Pertaining to Embryonic Stem Cell Research and Therapeutic Cloning in South Africa” 2010 *THRHR* 1 2.

<sup>11</sup> See specifically the reaction to “saviour siblings” in the United Kingdom.

<sup>12</sup> Those who are in favour of this development include most scientists and parents who seek to create a “saviour sibling”.

<sup>13</sup> The “slippery slope” is reference to “designer babies”. A “designer baby” is defined as “[an] artificial creation of human beings with certain pre-determined characteristics through modification of an early embryo’s genetic structure”. Human Fertilisation and Embryology: A Framework for Legislation November White Paper 1987 par 37. In other words, these are children who have been designed to be a certain gender, to have a particular eye and hair colour, to be of a certain intelligence level and so on. Currently, gender selection is available in the United States of America. Elsewhere, sex selection is prohibited unless there is a sex-linked disease in the family. Doctors in America recently had to put a hold on their plans to offer parents the option of selecting eye and hair colour, due to the overwhelming negative response from the public. See *Carte Blanche Medical: Designer Babies* (2010).

<sup>14</sup> The legality relates to their creation and purpose.

<sup>15</sup> *De Reuck v Director of Public Prosecutions (Witwatersrand Local Division)* 2004 (1) SA 406 (CC) par 55.

<sup>16</sup> Constitution of the Republic of South Africa, 1996.

<sup>17</sup> S 12(2)(a) of the Constitution.

<sup>18</sup> Currie and De Waal *The Bill of Rights Handbook* (2005) 308. The techniques referred to include in-vitro fertilization (IVF), preimplantation genetic diagnosis (PGD) and human leukocyte antigen (HLA) tissue typing.

<sup>19</sup> People have children for a number of reasons. Some have children to show their love, others have them to increase the size of the labour force, and still there other people who have children to change the family dynamics. Therefore, the decision to have a “saviour

other hand, are not necessarily affected by the reproductive rights and motivations on the part of parents, as are “saviour siblings”. However, through their genetic make-up, “benefactor children” serve the same purpose as “saviour siblings”, that is to save the life of a sick sibling.

The above issues pose a number of questions, which impact directly upon the rights of children, including: Whether the legal position of “saviour siblings”, as well as the techniques used in their creation, is regulated in South African law? Does a person’s right to reproductive autonomy, as guaranteed by the Constitution, justify interference with an embryo? Furthermore, can a parent consent to any and all procedures being carried out on a child? More specifically, can a parent consent to a tissue or organ transplant from one child to another? Does a “benefactor child” or “saviour sibling” have the right to consent to or refuse medical treatment that may save the life of a sibling?

This contribution aims to explain how the constitutional rights to bodily integrity and autonomy affect, firstly, “saviour siblings” and, secondly, “benefactor children”.<sup>20</sup> Furthermore, the article considers whether parents, in terms of South African law, have the right to make decisions concerning medical treatment and surgical procedures of this nature, on behalf of their child.

## **2 TOMORROW’S MEDICINE – “SAVIOUR SIBLINGS” AND “BENEFACTOR CHILDREN”: A MEANS TO AN END?**

Children are the bearers of rights, including international and regional rights. As the bearer of rights, children have the right to health and to participate in the making of decisions that have an influence on the right to health. In South African law, recent developments have led to changes in the age of consent for medical treatment and surgery. The newly operational Children’s Act has brought about a lowering in the age of consent from the ages of fourteen and eighteen respectively to the uniform age of twelve. Therefore, children of twelve years and older are recognized as being capable of consenting to their own medical treatment and surgical procedures. Children below the age of twelve are, however, still viewed as being incapable of making decisions of this magnitude and require parental consent when it comes to medical treatment and surgical operations. The fact that parents can consent on behalf of a child is potentially problematic for the two special groups of children addressed in this contribution, namely “saviour siblings” and “benefactor children”.

Rapid advancements in the scientific, medical and technological fields over the last few decades have given rise to numerous ethical issues and

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sibling” to save the life of a sick sibling, can be viewed as a reason why a couple has a child.

<sup>20</sup> “Saviour siblings” will be considered first and then “benefactor children”, as the concept of “benefactor children” came about as a result of questions prompted by the issue of “saviour siblings”.

debates. Historically, the main issues confronting society centred on the destruction of life,<sup>21</sup> at both the beginning and end of such life.<sup>22</sup> In the 21<sup>st</sup> century, the greatest ethical concern surrounds the creation and manipulation of life, undoubtedly due to the scientific discovery of DNA<sup>23</sup> during the 20<sup>th</sup> century.<sup>24</sup> The discovery of DNA and its double helix structure has allowed scientists the opportunity and increasing ability to study the entire human genome,<sup>25</sup> which has the propensity to enable those within the scientific profession to manipulate and alter genetic sequences for their own benefit, as well as for the benefit of a select few.<sup>26</sup> Although it is human nature to evolve, there is a responsibility not to venture so far into the scientific realm that it will result in untoward consequences for future generations.<sup>27</sup> In fact, it has been argued that should society continue to allow unrestricted and unrestrained advances in the fields of medicine, science and, more specifically, genetics, it could result in a pandemic of "... threats to our liberty, erosion of our autonomy and a diminution in our moral values".<sup>28</sup>

Though there are multiple developments occurring in the fields of medicine and science, it is the legal and ethical issues stemming from "new biotechnology"<sup>29</sup> that are the focus here, with particular attention being paid

<sup>21</sup> Wyatt "The New Biotechnology" in Stott *Issues facing Christians Today* 4ed (2006) 419. The fourth edition was fully revised and updated by Roy McCloughry.

<sup>22</sup> Destruction of life at the beginning refers to abortion and destruction at the end of life refers to euthanasia. Abortion is legal in South Africa as confirmed by CoToPA and to a lesser degree by s 12 of the Constitution. Active euthanasia is currently illegal in South Africa. However, a patient has the right to refuse medical treatment which can result in the premature termination of a person's life.

<sup>23</sup> The scientific definition of DNA is "[a] macromolecule usually consisting of antiparallel polynucleotide chains held together by hydrogen bonds, in which the sugar residues are deoxyribose. The primary carrier of genetic information." Klug and Cummings *Essentials of Genetics* G-5. DNA was discovered by James Watson and Francis Crick in 1953. In recognition of their contribution to science, both men, along with Maurice Wilkins, were the recipients of the Nobel Prize in Physiology or Medicine in 1962. Nobelprize.org "The Discovery of the Molecular Structure of DNA- The Double Helix" [www.nobelprize.org/educational/medicine/dna\\_double\\_helix/readmore.html](http://www.nobelprize.org/educational/medicine/dna_double_helix/readmore.html) (accessed 2011-11-19).

<sup>24</sup> Dhai, McQuoid-Mason and Van Bogaert "Issues in Genetics" in Dhai and McQuoid-Mason (eds) *Bioethics, Human Rights and Health Law: Principles and Practice* (2011) 111.

<sup>25</sup> "The genome is the entire set of genetic instructions found in a cell. In humans, the genome consists of 23 pairs of chromosomes, found in the nucleus, as well as a small chromosome found in the cells' mitochondria. These chromosomes, taken together, contain approximately 3.1 billion bases of DNA sequence." National Human Genome Research Institute "Genome" <http://www.genome.gov/Glossary/index.cfm?id=90> (accessed 2011-07-13). The Human Genome Project was established to determine the complete sequence of the DNA subunits, to identify all human genes, and to make them accessible for further biological studies.

<sup>26</sup> Dhai *et al* in Dhai and McQuoid-Mason (eds) *Bioethics, Human Rights and Health Law: Principles and Practice* 111.

<sup>27</sup> See Glover *Ethics of New Reproductive Technologies: The Glover Report to the European Commission* (1989) 159.

<sup>28</sup> Dhai *et al* in Dhai and McQuoid-Mason (eds) *Bioethics, Human Rights and Health Law: Principles and Practice* 111.

<sup>29</sup> New biotechnology includes the technologically assisted conception of a child for purposes of organ donation ("saviour siblings"). Jacob in Freeman (ed) *Children's Health and Children's Rights* 219.

to the effects of this advancement on two specific categories of children and their rights to bodily integrity and autonomy.<sup>30</sup>

### 3 A NEW WAY OF ORGAN AND TISSUE DONATION – THE AGE OF “SAVIOUR SIBLINGS” AND “BENEFACTOR CHILDREN”

Ever so often, the only medical chance that a child has of surviving a serious sickness is through a compatible tissue (or organ) donation from a sibling.<sup>31</sup> Siblings are generally considered to be the best donors, although an exact match between siblings only occurs 25% of the time.<sup>32</sup> Furthermore, where one child already suffers from a hereditary genetic disease, there is a 1 in 4 chance that another child from the same family (siblings) will be affected by the same disease.<sup>33</sup> In the past, unless there was a compatible tissue match within the family, the only option was to be put onto a transplant list and hope that a compatible organ donor would be found in time.<sup>34</sup>

Through current advancements in science, families (where there are presently no compatible matches) are able to resort to reproductive techniques which allow for the creation of a perfectly matched and healthy child (“saviour siblings”), who will provide the lifesaving tissue or organ.<sup>35</sup> Not every situation, however, demands or necessitates the creation of a “saviour sibling”, as a current sibling may also prove to be a tissue match (“benefactor children”), thus obviating the need for “saviour sibling” creation.

In this article, both “benefactor children” and “saviour siblings” will be considered in regard to the problems associated with these categories of children (specifically focusing on the age group below twelve) and how the law is to be applied to resolve these problems.<sup>36</sup>

<sup>30</sup> This contribution will also consider what impact this “new biotechnology” has on the best interests of the child/children.

<sup>31</sup> Human Fertilisation and Embryology Authority *Annual Report* (2003/04) 15.

<sup>32</sup> Siblings are generally considered to be better donors, as they share a great deal of the same genetic material. As a result, there is less chance of organ rejection. Furthermore, siblings are generally close in age and size, which helps the body to better accept an organ. See Anderson “Encouraging Bone Marrow Transplants from Unrelated Donors: Some Proposed Solutions to a Pressing Social Problem” 1993 *University of Pittsburgh LR* 477 482. Humans inherit half of their HLA type from their mother and the other half from their father. This results in each sibling having a one in four chance of being identically matched to a sibling. In other words, a 25% chance of being a match. However, considering the size of the average family, the chance of having a sibling that is tissue-matched, drops to 15%. See Devolder “Preimplantation HLA Typing: Having Children to Save Our Loved Ones” 2005 *J Med Ethics* 582.

<sup>33</sup> Braude *et al* 2002 3 *Nature Reviews Genetics* 953. The Hashmi family tried to have another child after Zain, without the use of modern day science. Mrs Hashmi fell pregnant, but terminated the pregnancy on discovering that the unborn child was also ill with *Beta Thalassaemia*.

<sup>34</sup> Presently, there are 3500 people waiting for organ transplants in South Africa. See <http://www.odf.org.za/> (accessed 2011-10-06).

<sup>35</sup> Hocking and Ryrstedt in Hocking (ed) *The Nexus of Law and Biology: New Ethical Challenges* 3.

<sup>36</sup> The problems that have been identified with these two groups are firstly, that these children are tissue matches to sick siblings and therefore, are subjected to procedures to save sick

## 4 “SAVIOUR SIBLINGS”

In 1978, the world witnessed the birth of the very first “test tube” baby, Louise Brown, following the collaboration of physiologist Robert Edwards and gynaecologist Patrick Steptoe.<sup>37</sup> From what was described “as a singular moment in human evolution”, the field of genetic research (science) has continued to progress, with most of society becoming more accepting of these advancements as they develop.<sup>38</sup> One of the more recent developments, which has been highlighted due to several documentaries and publications,<sup>39</sup> is the creation of one child to save the life of another.<sup>40</sup> This is known as the creation of the “saviour sibling”.

### 4.1 Definition and technique

A “saviour sibling”, as has already been defined, is a child who was conceived and selected as an embryo by his or her parents, specifically to be an organ or tissue donor for an ill sibling.<sup>41</sup> Traditionally, “saviour siblings” are referred to by this name, but there are alternative names that have been used to describe these children. These include “donor babies” or “loved children”. Conversely, the controversial and stereotypical nature of “saviour siblings” is reflected in the names “slave child” and “harvest child”.<sup>42</sup>

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siblings; secondly, South African law states that children under the age of twelve require parental consent before medical treatment or surgeries can be performed, which means that a parent can force/consent to a procedure on a child that can save a sick child. Thirdly, parents of “benefactor children” and “saviour siblings” do not always act in the best interests of these children. A further problem with “saviour siblings” is that these children are born solely to save the life of a sick sibling and, as a result, certain techniques are used to ensure that they will be a perfect match to the sick sibling.

<sup>37</sup> Silver *Remaking Eden: Cloning and Beyond in a Brave New World* (1997) 224–225. For his efforts, contribution and ultimate development of IVF technology, Robert Edwards was awarded the Nobel Prize in Physiology or Medicine in 2010. The summary as written by the Nobel Prize Organisation [www.nobelprize.org/nobel\\_prizes/medicine/laureates/2010/press.html](http://www.nobelprize.org/nobel_prizes/medicine/laureates/2010/press.html) (accessed 2011-11-19).

<sup>38</sup> Silver *Remaking Eden: Cloning and Beyond in a Brave New World* 224–225 as quoted in Wyatt in Stott *Issues facing Christians Today* 419.

<sup>39</sup> Documentaries and publications on this topic include: *A Baby to Save Our Son – Documentary* (2003); *Carte Blanche Medical: Designer Babies* (2010); the movie *My Sister’s Keeper* (2009); and Picoult *My Sister’s Keeper* (2003).

<sup>40</sup> Other developments of an equally sensitive nature include the so called “designer baby”.

<sup>41</sup> See further Jacob in Freeman (ed) *Children’s Health and Children’s Rights* 219. A “saviour sibling” has also been defined as “a child selected as a result of genetic screening to have some innate characteristic that will help save the life of an existing brother or sister”. See Hocking and Ryrstedt in Hocking (ed) *The Nexus of Law and Biology: New Ethical Challenges* 2. A “saviour sibling” differs from a “designer baby” in that a “saviour sibling” is created specifically to heal an ailing sibling, whereas a “designer baby” has been designed to meet a variety of parental specifications. The term “saviour sibling” is reported as having first appeared in the *Journal of Medical Ethics* October 2002.

<sup>42</sup> “Slave child” is the name that Richard Nicholson, author of “Bulletin of Medical Ethics”, has attached to “saviour siblings”. As will be seen below, there have been several cases of “saviour siblings” who were “engineered” to save ill siblings. One such “saviour sibling” is Jamie Whitaker, who has been labelled as a “harvest baby”. See Britten “‘Saviour Sibling’ Cures Sick Older Brother” 7 May 2011 *The Telegraph* <http://www.telegraph.co.uk/health/healthnews/8499394/Saviour-sibling-cures-sick-older-brother.html> (accessed 2011-10-05).

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"Saviour siblings" are "engineered" through the combined use of several medical procedures and techniques. These include in-vitro fertilization (IVF), pre-implantation genetic diagnosis (PGD) and human leukocyte-antigen (HLA) tissue typing.<sup>43</sup> A step-by-step description or explanation of the procedures used in the "engineering" of "saviour siblings" is provided below.

A "saviour sibling" is "engineered" in the following manner:

1. A woman undergoes normal IVF treatment in order for doctors to collect and fertilize her eggs.
2. Once these eggs have been fertilized, an embryo (or embryos, depending on the number of eggs that were "harvested") generally begins to grow. The embryo/s are grown in a laboratory for two to three days until the cells have divided and each embryo consists of about 8 cells.
3. A trained embryologist then removes one or two cells known as blastomeres, from each of the embryos.<sup>44</sup>
4. These removed cells are then tested to determine if the embryos from which these cells were removed contain the gene that causes the genetic condition in the family or sick child.<sup>45</sup>
5. In addition to screening for the genes which cause the genetic condition, a technician will put the same cells of the embryos through a series of tests, to determine the tissue type of the embryos. The results of these series of tests will determine if the embryo is an HLA tissue match to the sick sibling.<sup>46</sup>
6. Embryos that are unaffected by the genetic condition and which have the same HLA tissue type as the sick child, will then be transferred to the womb. (The couple undergoing the procedure normally selects one or two embryos that are unaffected, to be placed in the womb.)<sup>47</sup>
7. If any of the embryos are not used straight away, they are frozen. However, embryos that are carriers of a disease or affected embryos will be allowed to perish.
8. Following a two-week waiting period (after the unaffected embryo was first implanted into the womb), a pregnancy test is performed to

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<sup>43</sup> PGD can only be performed on an embryo, where the genes for the disease being screened or tested have been identified. Jamie Whitaker was not able to be screened for Diamond Blackfan Anaemia (DBA) as an embryo, as not all the genes for DBA could be screened at the time.

<sup>44</sup> A blastomere means "an undifferentiated embryonic cell, derived from a blastocyte". See GN R 7 in GG 29526 of 2007-01-05.

<sup>45</sup> PGD is used in steps 3 and 4.

<sup>46</sup> HLA tissue typing techniques are used in step 5.

<sup>47</sup> One or two embryos are generally selected, as any more embryos may severely impact on the amount of blood and stem cells that will be collected at birth. See *A Baby to Save Our Son – Documentary* (2003). The Whitakers, after undergoing the selection of embryos, had three viable embryos to choose from. They decided to implant only two, based on the advice of their doctor, which was that any more than two embryos could potentially limit the amount of blood available for collection at the birth.

determine whether the embryos have developed and whether the procedure has been successful or not.<sup>48</sup>

The success rate of “engineering” a “saviour sibling” by using the combination of IVF, PGD and tissue typing, is as low as 3 out of 16 embryos.<sup>49</sup> Presently, scientists are able to screen for approximately 100 diseases.<sup>50</sup> However, not all diseases are capable of being screened, as the specific genes have not been identified. Therefore, there is a potential risk of having another child who may be an exact match, but who also suffers from the same disease as the already ill sibling.<sup>51</sup>

## 4 2 International and foreign law

“Genetic research is presenting us with a rapidly developing and novel state of affairs. We may applaud this development, or condemn it. We may embrace it, seek to suppress it or simply find ourselves concerned about where it is leading. We may decide to face it individually, or collectively. The one thing we cannot afford to do is ignore it ...”<sup>52</sup>

Although it is an issue having international recognition and reach, the issue of “saviour siblings” is not regulated by international law.<sup>53</sup> To date, there is a noticeable lack of provisions regulating both the techniques used to create “saviour siblings” and the purposes for which these children are designed. Despite there being a lack of regulatory provisioning in international law, the techniques and purposes of “saviour siblings” are regulated by individual countries. In some of these countries, the matter of “saviour siblings” is regulated by both domestic law and the regulatory provisions of regional instruments.<sup>54</sup>

A consideration of foreign law is particularly relevant to this discussion, in view of the fact that South African law has not developed in the area of genetic research to the same extent as that of some countries around the world. Furthermore, section 39(1)(b) and (c) of the Constitution necessitates the consideration of both international and foreign law.<sup>55</sup>

<sup>48</sup> Human Fertilisation and Embryology Authority “Pre-implantation genetic diagnosis (pgd)” <http://www.hfea.gov.uk/preimplantation-genetic-diagnosis.html> (accessed 2011-10-12).

<sup>49</sup> The total of 3 in 16 embryos is calculated in the following way: each embryo has a 1 in 4 chance of being a tissue match. Each embryo also has a 3 in 4 chance of not being affected by the same disease. When calculated together, this works out to be that each embryo has a 3 in 16 chance of being the exact embryo that is being looked for. See Braude *et al* 2002 3 *Nature Reviews Genetics* 953.

<sup>50</sup> According to the Human Fertilisation and Embryology Authority, genes for over 100 diseases can be screened.

<sup>51</sup> This was the dilemma that the Whitaker family faced. As DBA could not be tested for when using PGD, there was no guarantee whether Jamie would be healthy or sick.

<sup>52</sup> Extract from the foreword of Human Genetics Commission *Making Babies: Reproductive Decisions and Genetic Technologies Report* 4. The foreword was written by Baroness Helena Kennedy QC, Chair of the Human Genetics Commission.

<sup>53</sup> The UNCRC does not mention the procedures used in the creation of “saviour siblings”.

<sup>54</sup> Eg, the United Kingdom. A discussion on the United Kingdom’s national law with respect to “saviour siblings”, is undertaken in the paragraphs below.

<sup>55</sup> S 39(1) of the Constitution states: “When interpreting the Bill of Rights, a court, tribunal or forum – ...”

The European Convention on Human Rights and Biomedicine<sup>56</sup> does not expressly recognize “saviour siblings”. It is, however, submitted that the Convention does indirectly acknowledge the concept and sanction the techniques and purposes associated with this matter. This submission is based on the interpretation of several sections within the Convention’s text, as well as in the text of Additional Protocol to the Convention on Human Rights and Biomedicine, on Transplantation of Organs and Tissues of Human Origin.<sup>57</sup>

The Convention is cognizant of the fact that science is continually progressing, and that it should do so for the benefit of future generations.<sup>58</sup> However, it also acknowledges that the potential for misuse exists, jeopardizing future generations. As a result, the Convention recognizes that the welfare of the individual prevails over science and society.<sup>59</sup>

Chapter IV (Human Genome) of the European Convention includes provisions that have been written in direct response to the advances within genetic research. It is under this chapter that provision for some of the techniques used to create a “saviour sibling” can be found.

Article 14 determines that techniques of medically assisted procreation may not be used to choose the sex of a future child. Medically assisted procreation techniques include IVF. Therefore, IVF may not be utilized to select the sex of a child, but there is no limitation in its use of “engineering” “saviour siblings”.

Although the Convention prohibits sex selection, it does allow for predictive genetic tests. In terms of Article 12:

“[t]ests which are predictive of genetic diseases or which serve either to identify the subject as a carrier of a gene responsible for a disease or to detect a genetic predisposition or susceptibility to a disease may be performed only for health purposes or for scientific research linked to health purposes, and subject to appropriate genetic counselling.”

Article 12 must be interpreted to include the right to carry out diagnostic interventions on an embryo, to determine whether the embryo carries a hereditary gene that will lead to serious illnesses in the future.<sup>60</sup> In other words, Article 12 can be interpreted as making provision for PGD.

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- b. must consider international law; and
  - c. may consider foreign law.”

<sup>56</sup> 1997. In terms of art 2(2)(a) of Additional Protocol to the Convention on Human Rights and Biomedicine, concerning Genetic Testing for Health Purposes (2008), the protocol does not apply to genetic tests carried out on a human embryo or foetus. In terms of art 2(2) of Additional Protocol to the Convention on Human Rights and Biomedicine, concerning Biomedical Research, the Protocol does not apply to research on foetuses, embryos *in vivo* or *in vitro*.

<sup>57</sup> 2002.

<sup>58</sup> Preamble to the European Convention on Human Rights and Biomedicine.

<sup>59</sup> Preamble and art 2 of the European Convention on Human Rights and Biomedicine. This statement reflects the obligation not to venture so far into the scientific realm, that it will result in untoward consequences for future generations.

<sup>60</sup> European Convention on Human Rights and Biomedicine Explanatory Report Chapter IV art 12.

Further recognition of “saviour siblings” can be found within the articles of Additional Protocol to the Convention on Human Rights and Biomedicine, on Transplantation of Organs and Tissues of Human Origin.<sup>61</sup> Article 2 states “[t]he provisions of this Protocol applicable to tissues shall apply also to cells, including haematopoietic stem cells”. Article 14 makes provision for the removal of stem cells or regenerative tissue from a sibling donor, even when the donor lacks capacity to consent.<sup>62</sup> Article 14 states:

- “1 No organ or tissue removal may be carried out on a person who does not have the capacity to consent under Article 13 of this Protocol.
- 2 Exceptionally, and under the protective conditions prescribed by law, the removal of regenerative tissue from a person who does not have the capacity to consent may be authorised provided the following conditions are met:
- (i) there is no compatible donor available who has the capacity to consent;
  - (ii) the recipient is a brother or sister of the donor;
  - (iii) the donation has the potential to be life-saving for the recipient;
  - (iv) the authorisation of his or her representative or an authority or a person or body provided for by law has been given specifically and in writing and with the approval of the competent body;
  - (v) the potential donor concerned does not object.”

Should the removal of tissue not be in the best interests of the donor sibling, Article 2 of the Convention requires the welfare of the individual (child) to be put above the interests of society and science.

Despite the regional acceptance of genetic research, the selection of a person is strongly prohibited. The European Charter of Fundamental Rights prohibits “eugenic practices in particular those aiming at the selection of persons”. From this provision, it can be inferred that, presently, babies that are designed to meet certain parental specifications (“designer babies”) will not be allowed.<sup>63</sup> However, the potential for “designer babies” does exist.

National attitudes towards “saviour siblings” vary considerably from one country to another. Countries such as Germany,<sup>64</sup> Austria<sup>65</sup> and Italy<sup>66</sup> have enacted legislation that prohibits PGD, whereas countries such as Sweden<sup>67</sup>

<sup>61</sup> For purpose of clarity, the Additional Protocol is written as Additional Protocol to the Convention on Human Rights and Biomedicine, on Transplantation of Organs and Tissues of Human Origin. Throughout the researching of this Additional Protocol, all references are referred to this Protocol in the above manner. This is why a comma appears between the words “biomedicine” and “on”.

<sup>62</sup> The provisions of the NHA are very similar to this.

<sup>63</sup> A “designer baby” is defined as an “artificial creation of human beings with certain pre-determined characteristics through modification of an early embryo’s genetic structure”. See Human Fertilisation and Embryology Authority: A Framework for Legislation November 1987 White Paper par 37.

<sup>64</sup> See the Embryo Protection Act 1990.

<sup>65</sup> Reproductive Medicine Act 275 of 1992.

<sup>66</sup> Assisted Reproductive Law 40 of 2004.

<sup>67</sup> Chapter 4 s 2 of the Genetic Integrity Act 351 of 2006 states “PGD may not be used without the permission of the National Board of Health and Welfare to try and have a child with a set of genes that enables the child to become a donor of blood-stem cells to a severely ill

and the United Kingdom have implemented legislation which accepts the techniques and purposes associated with "saviour siblings".

#### 4.2.1 United Kingdom<sup>68</sup>

Although the world's first "saviour sibling" was born in the United States of America,<sup>69</sup> it is the United Kingdom's system of regulation and decision-making in assisted reproduction and embryo research that is admired.<sup>70</sup> As the frontrunner in assisted reproduction and genetic research regulations, researchers in England are well aware of the "scientific, medical, psychological, social and ethical dimensions of embryo research".<sup>71</sup> It can therefore be said that English law is mindful of the varying moral and religious implications and core beliefs of society, and thus best reflects the attitude to be adopted towards the developing nature of science. The clearest example of this is the amended Human Fertilisation and Embryology Act of 2008 (HFE Act).

The implementation of amendments through the HFE Act<sup>72</sup> has seen a number of perceived controversial matters being regulated. These include the regulation of human admixed embryos,<sup>73</sup> the granting of licences for

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sibling. Permission may only be given if there are exceptional grounds for allowing such use."

<sup>68</sup> In addition to the foreign regional documents above, the discussion of foreign law will be restricted to the law of the UK. The reasons for this decision are firstly, the UK provides case law clearly demonstrating the controversial nature of this matter and, secondly, UK legislation is discussed, as considering the law of each State in both the United States and Australia, would be time-consuming and detract from the theme of this contribution.

<sup>69</sup> Adam Nash is regarded as the world's first "saviour sibling". He was created to be a tissue match to his older sister Molly who suffered from *Fanconi's Anaemia*. See Josefson "Couple Select Healthy Embryo to Provide Stem Cells for Sister" 2007 *BMJ* 321 <http://www.bmj.com/content/321/7266/917.1.full> (accessed 2011-10-10).

<sup>70</sup> Leather "Chair's Introductory" in Human Fertilisation and Embryology Authority (2003/2004) *Annual Report 2*.

<sup>71</sup> Human Fertilisation and Embryology Authority (2003/2004) *Annual Report 13*.

<sup>72</sup> 2008.

<sup>73</sup> See s 4A of the Human Fertilisation and Embryology Act 2008. "In terms of section 4A(6) a human admixed embryo is –

- (a) an embryo created by replacing the nucleus of an animal egg or of an animal cell, or two animal pronuclei, with –
  - (i) two human pronuclei,
  - (ii) one nucleus of a human gamete or of any other human cell, or
  - (iii) one human gamete or other human cell,
- (b) any other embryo created by using –
  - (i) human gametes and animal gametes, or
  - (ii) one human pronucleus and one animal pronucleus,
- (c) a human embryo that has been altered by the introduction of any sequence of nuclear or mitochondrial DNA of an animal into one or more cells of the embryo,
- (d) a human embryo that has been altered by the introduction of one or more animal cells, or
- (e) any embryo not falling within paragraphs (a) to (d) which contains both nuclear or mitochondrial DNA of a human and nuclear or mitochondrial DNA of an animal ("animal DNA") but in which the animal DNA is not predominant.

(7) In subsection (6) –

embryo testing and the granting of licences in certain circumstances for sex selection. It is through the implementation of regulations pertaining to embryo testing that provision is made for “saviour siblings” in English law. Schedule 2 paragraph 1 section 1ZA(1)(d) of the HFE Act<sup>74</sup> states:

“[a] licence under paragraph 1 cannot authorise the testing of an embryo, except for one or more of the following purposes – (d) in a case where a person (‘the sibling’) who is the child of the persons whose gametes are used to bring about the creation of the embryo (or of either of those persons) suffers from a serious medical condition which could be treated by umbilical cord blood stem cells, bone marrow or other tissue of any resulting child, establishing whether the tissue of the resulting child would be compatible with that of the sibling.”<sup>75</sup>

The section of law referred to above is the position currently held in the UK with regards to “saviour siblings”. Prior to the operation of the amendments in October 2009, a more cautious approach was adopted in regard to licensing “saviour siblings”. This approach can be evidenced in the cases of Hashmi and Whitaker.

Zain Hashmi (6) suffered from a serious genetic disorder – Beta Thalassaemia Major.<sup>76</sup> Beta Thalassaemia prevents bone marrow from producing enough red blood cells. As a direct consequence of this, Zain needed regular blood transfusions and drugs. There was, however, potential for Zain to lead a normal life with a transplant of stem cells from a compatible tissue donor.<sup>77</sup> Unfortunately, the chances of finding a compatible donor were extremely small.<sup>78</sup> As a result, the Hashmi’s approached the Human Fertilisation and Embryology Authority (HFEA), seeking permission to create a sibling that would be both Beta Thalassaemia free and a tissue match to Zain.

The couple was granted permission to undergo both PGD and HLA tissue typing, to ensure a match for Zain.<sup>79</sup> This decision was later challenged by Josephine Quintavalle on behalf of CORE (Comment on Reproductive Ethics) in the case of *R v HFEA*,<sup>80</sup> on the grounds that the HFEA did not have the authority to license these procedures.<sup>81</sup>

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(a) references to animal cells are to cells of an animal or of an animal embryo, and

(b) references to human cells are to cells of a human or of a human embryo.”

<sup>74</sup> 2008.

<sup>75</sup> Schedule 2 par 1ZA(1)(a) and (b) make provision for the use of PGD.

<sup>76</sup> *Quintavalle v HFEA* [2005] UKHL 28 Lord Hoffman par 2.

<sup>77</sup> *Quintavalle v HFEA supra* Lord Hoffman par 3.

<sup>78</sup> All three of Zain’s older siblings were non-compatible matches. Mrs Hashmi fell pregnant a further two times after Zain, in the hopes of having a sibling that would be a match. Unfortunately, the one pregnancy resulted in an abortion and the other resulted in a healthy baby who was unfortunately a non-compatible match to Zain.

<sup>79</sup> Pattinson “Designing Donors” in Gunning and Holm (eds) *Ethics, Law and Society Volume 1* (2005) 251.

<sup>80</sup> [2002] EWHC 2785.

<sup>81</sup> *Quintavalle v HFEA supra* Lord Hoffman par 8. Pattinson in Gunning and Holm (eds) *Ethics, Law and Society Volume 1* 252.

In *R v HFEA*,<sup>82</sup> Maurice Kay J held that, under the licences the HFEA could award, tissue typing could not be authorized. The basis for this argument was that treatment licences could be granted only for an activity that the HFEA considered to be “necessary and desirable” for the purpose of assisting a woman to carry a child.<sup>83</sup> Maurice Kay J held that tissue typing was done to ensure tissue compatibility with an older sibling and that he did not consider this to be “necessary or desirable” to assist a woman in carrying her child.<sup>84</sup> Therefore, Maurice Kay J held that the HFEA acted outside the bounds of its authority.

When taken on appeal, the judges of the Court of Appeal held that the Human Fertilisation and Embryology Act<sup>85</sup> could be read to include helping a woman produce a child with stem cells that would be a match to another child.<sup>86</sup> Furthermore, the court deemed tissue typing to be a service that fell under the list of treatment services which the HFEA had the authority to license.<sup>87</sup> Based on this interpretation, the Court of Appeal reversed the decision of Maurice Kay J.<sup>88</sup>

Following the success of the Hashmi’s, the Whitakers, who had an equally ill child, approached the HFEA for permission to create a “saviour sibling”.<sup>89</sup> Charlie Whitaker suffered from Diamond Blackfan Anaemia (DBA), a disease affecting his blood. Similarly to Zain, Charlie had to undergo blood transfusions as a way to clean his blood. To lead a normal life, Charlie also required the transfer of stem cells from a compatible donor. The Whitakers approached the HFEA for permission to create a sibling who would be a compatible match to Charlie, but were refused. The reason given was that DBA could not be diagnosed by PGD and that embryo selection, based on tissue typing alone, was not allowed “because of the risk that a child born following the procedure might be damaged by a test undertaken solely for the benefit of a sibling”.<sup>90</sup>

The HFEA believed that there could be risks associated with the removal of one or two cells from an embryo for testing. As the risks were unknown, the HFEA adopted a cautious approach and held that screening an embryo for compatible tissue matches would be allowed only when an embryo biopsy was already taking place to screen for a disease. Having reviewed the implications of the techniques and the available evidence indicating no great harm to the embryo, the HFEA amended its stance on the matter.

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<sup>82</sup> *Supra* 2785.

<sup>83</sup> See Schedule 2 par 1(3) of Human Fertilisation and Embryology Act 1990 as well as s 2(1) of the Act.

<sup>84</sup> See *R v HFEA supra* 2785 par 17. See further Pattinson in Gunning and Holm (eds) *Ethics, Law and Society Volume 1* 252.

<sup>85</sup> 1990.

<sup>86</sup> *R v HFEA supra* 2785 par 48, 89 and 133 as cited in Pattinson in Gunning and Holm (eds) *Ethics, Law and Society Volume 1* 252.

<sup>87</sup> See Schedule 2 par 1(1)(d) of the Human Fertilisation and Embryology Act 1990.

<sup>88</sup> Read further the case of *Quintavalle v HFEA supra* 28 which dealt with the appeal of *R v HFEA* [2003] ECWA Civ 667. The House of Lords held the same opinion as the judges of the Court of Appeal.

<sup>89</sup> See *A Baby to Save our Son – Documentary* (2003).

<sup>90</sup> Human Fertilisation and Embryology Authority (2003/2004) *Annual Report* 13.

Furthermore, the Court of Appeal granted the HFEA the power to license embryo biopsies, which included the procedures of PGD and HLA tissue typing.<sup>91</sup> The granting of this permission should not be seen as the first resort to helping sick siblings. Rather, it should be considered after all other possibilities have been explored and proved to be non-viable options. Only then, and taking each case on its own merits, should the HFEA grant permission to create a “saviour sibling”.<sup>92</sup>

### 4 3 National legislation

Within the South African national legislative framework, the NHA<sup>93</sup> is central to health legislation.<sup>94</sup> With this in mind, the respective techniques and purposes associated with “saviour siblings” must be weighed against the provisions of the NHA and the accompanying regulations to determine the legal position of “saviour siblings” in South Africa. While sections of the NHA can equally be applied to “benefactor children”, there are differences between the two categories of children (“benefactor children” and “saviour siblings”). Therefore, “benefactor children” and the law applicable to these children, will be considered later in the article.

Despite the wide-ranging regulatory powers of the NHA, the Act (unlike the HFE Act of the UK) has no specific provision/s regulating “saviour siblings”.<sup>95</sup> Although a single express provision regulating “saviour siblings” is lacking, it could be interpreted that the regulation of “saviour siblings” is to be found through the reading together of several sections and regulations of the NHA. Following this pragmatic approach, sections 55 and 56 and Regulation 4(a)(vii) of the Regulations Regarding the Use of Human DNA, RNA, Cultured Cells, Stem Cells, Blastomeres, Polar Bodies, Embryos, Embryonic Tissue and Small Tissue Biopsies for Diagnostic Testing, Health Research and Therapeutics must be read together.

Section 55 states that tissue, blood, blood products or gametes may not be removed from a living person, for the purposes in section 56, without his/her written consent, and that the removal is done in accordance with prescribed conditions.

This section requires the written consent of the person from whom the tissue, blood or blood products is being removed. In compliance with section 129 of the Children’s Act, should the person be a child under the age of twelve, a parent or guardian may consent on behalf of that child. Where the child is over twelve years of age, the written consent must be given by the child.

Section 56 regulates the removal of tissue, blood, blood products or gametes. Of importance is section 56(2)(a)(ii) and (iv) which states that:

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<sup>91</sup> Human Fertilisation and Embryology Authority (2003/2004) *Annual Report* 15.

<sup>92</sup> *Ibid.*

<sup>93</sup> The NHA came into effect in May 2005, with the exception of Chapters 6 and 8.

<sup>94</sup> Carstens and Pearmain *Foundational Principles of SA Medical Law* (2007) 246.

<sup>95</sup> When compared to the HFE Act 2008 above, the lack of provisions is clearly noticeable.

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"the following tissue, blood, blood products or gametes may not be removed or withdrawn from a living person for any purpose contemplated in subsection 1 ... tissue which is not replaceable by natural processes from a person younger than 18 years ... or placenta, embryonic or foetal tissue, stem cells and umbilical cord, excluding umbilical cord progenitor cells".<sup>96</sup>

Section 56(1) does not list or define the medical or dental purposes for which blood and tissue may be withdrawn or removed from a living person. Instead, this subsection states that tissue or blood may be withdrawn only for the medical or dental purposes prescribed. The word "prescribed" is defined by the NHA as prescribed by regulation under section 90.<sup>97</sup> The Minister of Health has enacted regulations (Regulations Relating to the Withdrawal of Blood from a Living Person for Testing) that apply to section 56, however, these regulations do not define nor list medical and dental purposes for which blood, blood products and tissue may be withdrawn or removed.<sup>98</sup> Therefore, it is unclear for which medical or dental purposes tissue or stem cells may be removed. As a result, it cannot be said with absolute certainty whether the NHA regulates the purposes for which "saviour siblings" are created. Despite the lack of clarity, tissue that is not replaceable and stem cells may be removed if the Minister of Health has authorized their removal. The Minister may impose any conditions deemed to be necessary before this removal takes place.<sup>99</sup>

Regulation 4(a)(vii) of the Regulations Regarding the Use of Human DNA, RNA, Cultured Cells, Stem Cells, Blastomeres, Polar Bodies, Embryos, Embryonic Tissue and Small Tissue Biopsies for Diagnostic Testing, Health Research and Therapeutics states:

"preimplantation DNA tests following the removal of a polar body or one or two blastomeres of a developing embryo can be carried out for the purpose of ensuring implantation of an embryo, without a mutation that causes a serious genetic condition".

In other words, this particular regulation makes provision for the use of PGD to screen embryos for the genes of various diseases.<sup>100</sup> This Regulation is, however, a draft regulation and has therefore not been made final. As such, the provision is not yet operational and it is unclear from other legislation whether PGD and HLA tissue typing is allowed in South Africa.<sup>101</sup>

Based on the wording of the various sections and regulations, it is submitted that South African legislation does not currently (expressly) recognize "saviour siblings". However, there is potential within the law for the recognition of "saviour siblings". This can be achieved with very little effort and few changes to current legislation. For example, if the Regulations Regarding the Use of Human DNA, RNA, Cultured Cells, Stem Cells,

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<sup>96</sup> S 56(2)(a)(ii) and (iv).

<sup>97</sup> See s 1 of the NHA.

<sup>98</sup> See Regulations Relating to the Withdrawal of Blood from a Living Person for Testing.

<sup>99</sup> S 56(2)(b) of the NHA.

<sup>100</sup> Refer back to the explanation on how "saviour siblings" are created above.

<sup>101</sup> The provisions in the NHA do not mention PGD and tissue typing. However, the provisions of chapter 8 of the NHA are incomplete and unclear, so it cannot be said with certainty that the NHA does not regulate PGD and tissue typing.

Blastomeres, Polar Bodies, Embryos, Embryonic Tissue and Small Tissue Biopsies for Diagnostic Testing, Health Research and Therapeutics were to be finalized, and provisions for HLA tissue typing were included, the law would recognize and regulate “saviour siblings”, as these are the procedures used to create these children.

Furthermore, if the legislature, with the assistance of the Minister of Health, were to list the medical and dental purposes for which blood and tissue can be removed and included in this list, the removal of tissue, blood or blood products to treat a sick sibling, both the NHA and Regulations Relating to the Withdrawal of Blood from a Living Person for Testing would recognize and regulate “saviour siblings”.<sup>102</sup>

From the fact that the law does not expressly refer to “saviour siblings” and from the noticeable lack of South African case law and media attention on the matter, one can conclude that South Africa has not yet joined the ranks of countries which have had to answer the pleas of parents to allow them to create “saviour siblings”.<sup>103</sup> Should “saviour siblings” become a part of South African society in the near future, current law would need to be amended as suggested above. Without these amendments to the law, “saviour siblings” would not be properly regulated and their rights as the more vulnerable members of society would potentially be undermined and infringed upon.

The Constitution recognizes that everyone has the right to bodily integrity and autonomy, which includes the right to make decisions concerning reproduction.<sup>104</sup> It can be argued that the decision to “select” an embryo which is disease free and a tissue match to an already ill sibling, is protected by the right to reproductive autonomy. To prohibit PGD and tissue typing can be viewed as an interference with reproductive freedom.<sup>105</sup> The only justified reason for interfering with the reproductive autonomy of a person is when there is a risk of serious harm to others, including resulting children. Since research has shown that there are no immediate effects associated with PGD, and has yet to report any long term effects, there is no legitimate reason to interfere with or limit the right to reproductive autonomy.<sup>106</sup> However, the right to reproductive autonomy (as guaranteed by section 12(2)(a)) must be weighed against the rights of the resulting child, as

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<sup>102</sup> The recommendations made are based on the problems and sections of law mentioned above.

<sup>103</sup> Eg, countries such as the United States of America, the United Kingdom and Australia have all enacted law that regulates “saviour siblings” in some way.

<sup>104</sup> Ss 12(2), 12(2)(a) and 27 of the Constitution. Also see Du Plessis, Van der Walt and Govindjee “The Constitutional Rights of Children to Bodily Integrity and Autonomy” 2014 35(1) *Obiter* 1–23.

<sup>105</sup> Art 16(1) of the United Nations Declaration on Human Rights guarantees every man and woman of full age the right to found (establish or start) a family.

<sup>106</sup> It is also difficult to justify preventing parents from attempting to create a “saviour sibling” where they have a child with a life-threatening illness, who may be cured by a stem-cell transplant. Human Genetics Commission *Making Babies: Reproductive Decisions and Genetic Technologies Report* 14.

“constitutional rights are mutually interrelated and interdependent and form a single constitutional value system”.<sup>107</sup>

Children, like adults, have the right to bodily integrity and autonomy.<sup>108</sup> Therefore, it can be assumed that children are capable of making decisions and that any intervention or outside interference should, in general, be minimized.<sup>109</sup> However, for an embryo destined to be a “saviour sibling”, interference with the “body” begins long before the embryo or the “child to be” is recognized as a bearer of rights. Where PGD is carried out without tissue typing, it can be argued that this is done in the best interests of the embryo and, therefore, does not amount to an interference with bodily integrity. However, where PGD is combined with HLA tissue typing, it is submitted that this is not in the best interests of the embryo, but rather of the sick sibling, and amounts to an interference.<sup>110</sup> Statements of this nature are controversial in a country such as South Africa, where the law does not recognize an embryo as a legal subject which can be afforded rights.<sup>111</sup> There are those in society who believe that an embryo is more than a bundle of cells and is in fact, a potential baby.<sup>112</sup> As a result, the status of an embryo/foetus has been challenged.

One of the most well-known examples where this was challenged was in the case of *Christian Lawyers Association of South Africa v Minister of Health*.<sup>113</sup> Although this case dealt with the constitutionality of abortion, the principles can be applied to the status of the embryo.

Very briefly, in the case of *Christian Lawyers Association of South Africa*, the court was asked to determine whether Choice on Termination of Pregnancy Act (CoToPA) was unconstitutional and should be struck down. The reasons submitted in support of the claim of unconstitutionality were that abortion infringed on the right to life of an unborn child and that this right attached to the unborn child at the moment of conception.

After consideration, the court held that section 28, the children’s rights section did not expressly refer to a foetus or embryo in any of its provisions and, furthermore, that certain rights within this section could not be applied

<sup>107</sup> *De Reuck v Director of Public Prosecutions (Witwatersrand Local Division) supra* par 55.

<sup>108</sup> See further *Bhe v Magistrate, Khayelitsha (Commission for Gender Equality as Amicus Curiae)*; *Shibi v Sithole*; *South African Human Rights Commission v President of South Africa* 2005 (1) SA 580 (CC) par 52. See also Kruger “The Protection of Children’s Rights in the South African Constitution: Reflecting on the First Decade” 2007 *THRHR* 241.

<sup>109</sup> Interference with the decision-making process of a child should be allowed only where it is necessary to avert a necessary harm. This requires the application of the “test of irrationality”.

<sup>110</sup> Devolder 2005 *J Med Ethics* 582–586. Suzi Leather, former chair of the HFEA, when interviewed, described these tests as “biopsying” an embryo. Ms Leather also referred to the fact that when an embryo is biopsied, there are potential risks for the embryo, with all the benefits going to another person or sick sibling. See *A Baby to Save Our Son – Documentary* (2003).

<sup>111</sup> The legal status of children and the concept of legal subjectivity can be found in more detail in Boezaart “Child Law, the Child and South African Private Law” in Boezaart (ed) *Child Law in South Africa* (2009) 3 4.

<sup>112</sup> Human Fertilisation and Embryology Authority (2003/2004) *Annual Report* 13.

<sup>113</sup> 1998 (4) SA 1113 (T).

to an unborn child, such as the right to work or detention. Based on this observation, it was concluded that none of the other rights in the Bill of Rights could be applied to a foetus either.

In addition, the court observed that the use of the words “everybody” or “every person” did not extend to include a stillborn child, an unborn child, a viable unborn child, an unborn human being or a living foetus. As a result of all these observations and arguments, it was said that a foetus could not be afforded the right to life, as it was not considered to be a living person or legal subject. As such, a foetus or embryo could not be the bearer of rights.

Therefore, South Africa does not ascribe the status of legal subject to an individual, until that person is born. For this reason, it is submitted that it cannot be said that PGD with or without tissue typing, is or is not in the best interests of the embryo, as this would infer that an embryo/foetus does in fact have rights, which is incorrect.

Nevertheless, upon birth, a child is afforded both the status of a legal subject and the rights in the Bill of Rights.<sup>114</sup> That a child acquires rights only upon birth raises the question as to what right of redress a child (“saviour sibling”) has if any procedure performed on it as an embryo resulted in harm to its body, leading to subsequent deformity or other issues.<sup>115</sup> Although there are no reported cases of any harm caused or injury sustained as a result of PGD and HLA tissue typing, it has been said that when an embryo is “biopsied”, there were potential risks for the embryo.<sup>116</sup> Could principles similar to those of the *nasciturus* fiction be applied to the above mentioned scenario? In other words, for the sake of remedy and redress, can the child in question be said to have been alive at the time that the injury occurred? This would be acknowledging that at the time of injury, an embryo is a legal subject. Should such an incident arise, it is a question that would need to be

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<sup>114</sup> The legal subjectivity of a natural person is recognized as beginning at birth. See Boezaart in Boezaart (ed) *Child Law in South Africa* 4.

<sup>115</sup> That a person acquires rights only upon birth raises the question, what about the rights of a child that may never be born, for example, embryos that are surplus from IVF treatment? Some believe that these embryos are nothing more than cells, whereas others view the embryo as a “potential child”. Is it right that these “potential children” either be stored in a freezer for a period of time before being destroyed, or that they be used for research purposes? Can these embryos be afforded rights? Again, this is a matter for the courts and the legislature to decide. The approach followed by the British authorities may be an option to be considered in South Africa. In other words, strict legal controls need to be set in place to protect the embryo. Human Fertilisation and Embryology Authority (2003/2004) *Annual Report* 13. Current legislation in South Africa is incomplete and confusing, as are the draft regulations that attempt to regulate matters of a similar nature. See the NHA and Regulations Regarding the Use of Human DNA, RNA, Cultured Cells, Stem Cells, Blastomeres, Polar Bodies, Embryos, Embryonic Tissue and Small Tissue Biopsies for Diagnostic Testing, Health Research and Therapeutics.

<sup>116</sup> See *A Baby to Save our Son – Documentary* (2003). Through the course of this documentary, a number of interviews took place. Suzi Leather, the former chair of the HFEA, stated during her interview that when an embryo is biopsied there were potential risks for the embryo, with all the benefits going to another person or sick sibling. Another interview conducted with a technician at the medical institute where the Whitakers underwent the process of tissue typing embryos, said that there was potential for structural damage to an embryo if, during the process of screening and testing embryos, any extra manipulation is done to the embryo.

answered by a court in that, at this time, there are no known reported cases, precedent or law on this matter.

Children, like their adult counterparts, are entitled to the rights in the Constitution.<sup>117</sup> As seen from the discussion on the Bill of Rights, some of these rights are guaranteed in both section 28 and other sections of the Bill of Rights.<sup>118</sup> Those rights that appear to be repeated (in section 28) are described as background rights to the specific children’s rights in section 28. Those which are not repeated, however, are also applicable to children, such as the right to bodily integrity.<sup>119</sup> Young children are generally thought to lack the ability to give “autonomous donor consent”.<sup>120</sup> In terms of South African law, children have rights to bodily integrity and autonomy, but are deemed to be insufficiently mature by virtue of age to make decisions concerning their health care and treatment. As such, provisions in the newly operational Children’s Act<sup>121</sup> prescribe that parents may consent to the medical treatment or surgical procedures on behalf of a child who is below twelve years of age (or who is over the age but not mature enough). This is potentially problematic, especially with young “saviour siblings”, as provisions such as these give parents a right to consent to any treatment or surgery with very few restrictions.<sup>122</sup> The Constitution does not guarantee parents a right to control or make decisions on behalf of their children. Therefore, it can be argued that section 129, if applied without guidelines, will place children in the same category as property, and they will not be viewed as individuals with autonomous decisions and views.<sup>123</sup>

Section 31 of the Children’s Act, however, provides some assistance by directing parents to give due consideration to the views and opinions of children under the age of twelve, for whom they are consenting.<sup>124</sup> In terms of Article 12 of the UNCRC, due consideration requires more than merely

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<sup>117</sup> It is generally said that children are the bearers of all rights in the Bill of Rights, with the exception of s 19(3) of the Constitution. This is not correct, however, as there are other rights in the Bill of Rights which do not generally apply to children, for example, children do not have rights that prisoners have (s 35(2)) unless they are prisoners themselves. Furthermore, worker and employer rights (s 23(2)–(5)) do not apply to children unless they are workers or employers.

<sup>118</sup> Refer back to the discussion on the Bill of Rights and children’s rights under heading 4 6 – The Bill of Rights.

<sup>119</sup> S 12(2) of the Constitution. A child becomes a bearer of rights upon birth.

<sup>120</sup> All children under the age of 12 are considered by South African law to be incapable of consenting to medical treatment or surgery.

<sup>121</sup> Act 38 of 2005.

<sup>122</sup> The only restriction or limitation on a parent’s right to consent to medical treatment or surgery on a child under twelve, is that due consideration must be given to the views and wishes of that child. See s 129(4) and (5). In this way, parents are not theoretically able to consent to treatment or surgery as and how they please.

<sup>123</sup> *S v M* 2008 (3) SA 232 (CC) par 18, “Every child has his or her own dignity. If a child is to be constitutionally imagined as an individual with a distinctive personality, and not merely as a miniature adult waiting to reach full size, he or she cannot be treated as a mere extension of his or her parents, umbilically destined to sink or swim with them.”

<sup>124</sup> S 129(4) and (5) direct those who are consenting to the treatment or surgery of a child under 12 to observe the condition stated in s 31 of the Children’s Act. S 10 of the Children’s Act also recognizes that a child may participate in an appropriate manner in any matter concerning him or her. Both ss 10 and 31 comply with art 12 of the UNCRC.

listening to the views of children. Therefore, in order to comply with the condition imposed, a serious consideration of the opinions expressed by the child must be undertaken. Article 12 of the UNCRC does not prescribe an age limit when parents are required to consider the views of a child. However, for purposes of this discussion and, in compliance with South African law, parents must consider the views expressed by a child under the age of twelve, as those above this age are considered competent to make their own decisions. Due consideration must be given to both verbal and non-verbal expressions of the views of children. Non-verbal expressions of a child must be recognized, as a child below twelve may have the inability to use the appropriate words to express their opinion, but nonetheless understands the implications of treatment or surgery. Some writers are of the opinion that children should not only be allowed to participate, but should be able to make the decision in matters that may have long-term consequences for them.<sup>125</sup> This is a general statement which, if applied to South African law, could be interpreted as meaning that children under twelve should not have only a participatory right, but also a right to consent to any treatment or surgery that has potential long-term consequences for them.

Irrespective of who should be allowed to make the decision regarding surgery on a “saviour sibling”, it is absolutely clear that the best interests of that child must always be of paramount importance, as required by section 28(2) of the Constitution.<sup>126</sup> This imposes a duty on all (more so on parents) to respect the best interests of the child. But what must be done where parents fail to heed the best interests of a “saviour sibling” under the age of twelve? It has been reported that there are concerns about the well-being of a child who is a “saviour sibling”.<sup>127</sup> There are apprehensions that, once perceived as a “saviour”, it will become very difficult to set limitations as to when tissue or organs from a “saviour sibling” under twelve may be used for the benefit of the sick sibling.<sup>128</sup> Emotionally burdened parents of “saviour siblings” may potentially continue to resort to using a “saviour sibling” below the age of twelve, thereby putting the welfare of the sick child above the best interests of the “saviour sibling”.<sup>129</sup> In addition, parents may overlook the opinion of the child, and fail to consider the views and opinions of the “saviour sibling” before proceeding with the donation. This may well amount to a failure to consider the best interests of the “saviour sibling”, as well as an unintentional but gross violation of the right to security in and control over the body of such child.

<sup>125</sup> Presently, the long-term effects of PGD and tissue typing are unknown.

<sup>126</sup> In terms of s 129 of the Children’s Act, those who can consent to surgery on a child include parents, guardians, the Minister of Social Development, the superintendent of a hospital or a High Court or Children’s Court. Furthermore, the application of s 28(2) extends beyond the rights listed in s 28(1). This means that the application of the best interests of the child test will extend to other rights in the Bill of Rights, such as s 12. See Kruger 2007 *THRHR* 248 in general and *Minister of Welfare and Population Development v Fitzpatrick* 2000 (3) SA 422 (CC) par 17 specifically.

<sup>127</sup> Human Genetics Commission *Making Babies: Reproductive Decisions and Genetic Technologies Report* 14.

<sup>128</sup> *Ibid.*

<sup>129</sup> The Whitaker family said that they would continue to undergo the process of creating a “saviour sibling” until they had a child who would “save” Charlie.

This prompts the question, where two children are involved, whose best interests are considered to be of more importance? The law states that the best interests of the child are of paramount importance in all matters.<sup>130</sup> Therefore, both the best interests of the "saviour sibling" and the sick child must be considered to be of paramount importance. However, whose best interests are deemed to be of more importance? How are the competing interests of a "saviour sibling" and sick child to be balanced? Although the court has never had to decide on such a matter, it is suggested that, in order to resolve this problem fairly, the decision as to whose best interests are more important (either the "saviour sibling" or sick child) must be taken out of the hands of the parents and be given to a neutral third party. In other words, the ultimate decision as to which child's best interests are more important should be made by an impartial and neutral judge, with the assistance of a person such as the Family Advocate or an ombudsman.<sup>131</sup>

Furthermore, a National Board should be established to review each proposed case of "saviour siblings". This would include assessing the reasons why parents wish to create a "saviour sibling", thereby preventing parents using the guise of a "saviour sibling" to screen embryos for a particular gender or sex selection. This Board should consist of professionals in the fields of medicine and law. The HFEA, a National Board established in the United Kingdom, as part of its authority, reviews requests by various couples to create "saviour siblings". As UK law provides the most detailed provisions on "saviour siblings", South Africa would do well to follow a similar approach.

Although the concept of "saviour siblings" has yet to be introduced into South Africa, it is no longer a matter exclusively for the future. With funding secured, the Southern African Human Genome Project (SAHGP) will soon be established in South Africa. While still very much in its infancy, the potential long-term benefits of this project include finding new ways to diagnose, treat and prevent numerous diseases.<sup>132</sup> With this development, and the draft regulation law allowing PGD, it is only a matter of time before South Africa will begin to break "scientific" ground on this "new biotechnology". In the words of Dr Yvonne Holt, as medical science advances, "this regenerative medicine will definitely be part of the future".<sup>133</sup>

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<sup>130</sup> S 28(2) of the Constitution.

<sup>131</sup> The office of the Family Advocate was established primarily to help families resolve custody or maintenance arrangements that are in dispute, in order to finalize a settlement of divorce in the court. As a recognized neutral person, the Family Advocate is able to determine what is in the best interests of the child and would be helpful in assisting a judge to determine which child's best interests are more important. Likewise, the ombudsman, as a children's rights advocate, would be able to represent the children independently from their parents in the court, in addition to promoting their best interests.

<sup>132</sup> The way in which the SAHGP will attempt to treat diseases in the long term could include using stem cells and tissue from siblings or children that are specifically screened to be an exact genetic or tissue match.

<sup>133</sup> Dr Holt is the Medical Director of Netcells, a company in South Africa that provides storage for stem cells. Before South Africa welcomes this new biotechnology as a feasible treatment option, there are several problem areas which need to be addressed, the most pressing being irregular electricity supplies. If South African law should legalize "saviour siblings", various clinics and laboratories will require a constant and uninterrupted supply of

Therefore, South African law must continue to develop, otherwise it will be “in catch-up mode instead of shaping the expansion of the field”.<sup>134</sup> If the law does not put in place regulatory provisions now, “law [will be] formed in response to the legal and ethical conundrums”, as opposed to putting in place provisions to address the potential legal and ethical conundrums.<sup>135</sup>

## 5 “BENEFACTOR CHILDREN”<sup>136</sup>

It is estimated that more than seven million babies are born each year with a genetic disease or congenital abnormality.<sup>137</sup> In South Africa, reports have indicated that at least 1 in 40 babies are born with a defect.<sup>138</sup> Furthermore, there are over 150 000 children born annually who are affected by a genetic defect requiring a medical intervention by the age of five.<sup>139</sup> Not all of the defects and diseases that children present with can be cured through normal conventional treatment and there are some that are incurable. Other diseases, however, are treatable only through the donation of tissue or organs.<sup>140</sup> In situations requiring tissue or organ donations, the most likely suitable donor would be a family member. Where the donation is for a child, the most suitable donor would be a sibling. In the discussion above, emphasis was placed on the creation and use of “saviour siblings”. In this section, the discussion turns to the rights of a child who is a tissue match to an ill sibling, but who has **not** undergone PGD and HLA tissue typing to be a match. Put differently, this discussion will focus on the rights of children who fall within the 25% possibility of being a tissue match; that is, “benefactor children”.

The possibility of finding a tissue match in a family is generally very slim. The chances of finding a match in a parent is as low as 1 in 8, with a slightly improved chance amongst siblings, who share a 1 in 4 chance of being exact tissue matches. That a child is both a tissue match and disease free

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electricity. A steady supply of electricity is essential to keeping both embryos and cells alive and viable for transplant. In recent times, Eskom, South Africa’s electrical energy supplier, has experienced a number of equipment problems which have impacted on the consistency of the electricity it can supply. These problems will need to be fixed if we are to utilize this biotechnology effectively.

<sup>134</sup> Lyerly “*Test Tube Families: Why the Fertility Market needs Legal Regulation* by N R Cahn” 2009 361 *N Engl J Med* 429 430.

<sup>135</sup> *Ibid.* Should South Africa fail to regulate this matter, it has the potential for the development of international medical tourism. International medical tourism is the term used to describe those persons who leave their country and go abroad to escape the regulatory provisions of their own country. Once the Whitakers’ request for permission to have a “saviour sibling” in England was denied, the family went to the USA, to undergo the procedure. By going to the USA, they escaped the prohibitions of the law in the UK.

<sup>136</sup> “Benefactor” is defined as “a person who supports or helps a person, institution, etc.” *Collins Shorter English Dictionary* 99.

<sup>137</sup> Weatherall “The Inherited Diseases of Hemoglobin are an Emerging Global Health Burden” 2010 *Blood* 4331.

<sup>138</sup> These numbers reflect the results available in 2001. More recent statistics could not be found. Refer to the Department of Health <http://www.doh.gov.za/show.php?id=148> (accessed 2011-10-05).

<sup>139</sup> Department of Health <http://www.doh.gov.za/show.php?id=148>.

<sup>140</sup> These include Beta Thalassemia, Diamond Blackfan Anaemia and Fanconi’s Anaemia.

(without having undergone the procedures discussed above) is quite remarkable, and the decision by a parent to use the tissue or organ from one sibling to save the life of another sibling can easily be understood.

Within South African law, parents are able to consent to the medical treatment of or surgical operation on a child. This capacity to consent is, however, restricted to children under the age of twelve, due to the recent changes in law.<sup>141</sup> The newly operational section 129 of the Children’s Act states that parents of children under the age of twelve, have the right to consent to both the medical treatment of and operations on their child/children.<sup>142</sup> Section 129 can therefore be interpreted as providing parents with the authority to consent to the transplant of tissue or an organ from their healthy “benefactor child” (under the age of twelve) to their child in need.

Further supporting this right to consent is Regulation 3 of the Regulations Regarding the Use of Human DNA, RNA, Cultured Cells, Stem Cells, Blastomeres, Polar Bodies, Embryos, Embryonic Tissue and Small Tissue Biopsies for Diagnostic Testing, Health Research and Therapeutics, which allows a parent of a child under the age of twelve to consent to the removal of biological material for genetic testing.

However, the newly operational sections 55 and 56 limit what can be removed from a child (both a “benefactor child” and “saviour sibling”) and, therefore, limits a parent’s capacity to consent. Section 55 requires the written consent of the person from whom the tissue or other products is being removed. As section 129 of the Children’s Act specifically states that children under the age of twelve require parental consent, it is accepted that parental consent will be needed before blood, blood products or tissue may be removed from a “benefactor child” under twelve.

Section 56 limits what procedures a parent may consent to as it states:

“the following tissue, blood, blood products or gametes may not be removed or withdrawn from a living person... tissue which is not replaceable by natural processes from a person younger than 18 years ...”<sup>143</sup>

This section is unfortunately confusing, as it is not clear what amounts to tissue which is not replaceable by natural process or, for what medical purpose this tissue may or may not be removed. Therefore, before a medical procedure can be performed on a “benefactor child”, it will need to be determined if tissue that is being removed from a child under twelve is considered to be replaceable or non-replaceable. Should tissue not be replaceable but be required to save a sick sibling, the Minister of Health may

<sup>141</sup> In terms of the Children’s Act a uniform age of twelve has been set down as the age of consent, whereas the Child Care Act had imposed age limits of fourteen years for consenting to medical treatment and eighteen years for consenting to surgery.

<sup>142</sup> Guardians are also capable of consenting to a child’s surgery. Children over twelve are able to make the decision themselves, but they must be duly assisted by a parent or guardian. There is a noticeable lack of provisions in international and regional law stating at what age a child is entitled to consent to medical treatment or surgery. All that is provided is that each child has the right to health and the right to participate in matters that affect them.

<sup>143</sup> S 56(2)(a)(ii) of the NHA.

consent to its removal from a “benefactor child”, subject to any conditions that he or she wishes to impose.<sup>144</sup>

Though a parent has the capacity to make decisions and consent to medical procedures on their child, he or she should not consent to a transplant from one child to another where there is an adult who is a match and is willing to be a donor.<sup>145</sup> Furthermore, while it can be assumed that any child would want to help a brother or sister, a parent should not consent to treatment or surgery on a “benefactor child” under twelve where the likelihood of success is extremely low.<sup>146</sup> The effects of the failure of the treatment or operation can be more detrimental to this child than the operation itself. It is only once all available options have been explored and, following a consideration of the views of the “benefactor child”, that parents can feasibly consider consenting to the proposed operation.<sup>147</sup>

Should a “benefactor child” express an objection to the proposed treatment or surgery to remove tissue or an organ, his or her parents need to respect this objection.<sup>148</sup> Where a parent overrides a child’s (below twelve) refusal, it can be said that they fail to acknowledge that child as a source of wishes and fears and treat him or her as a mere means to an end.<sup>149</sup> This amounts to a potential infringement of a child’s right to security in and control over their body. Furthermore, parents do not derive a right from their power to consent to deal with a child as they see fit.<sup>150</sup> Where a parent consents to an operation which will cause the “benefactor child” to suffer from unnecessary harm or, where there is a risk of harm, all for the sake of the sick sibling, it can be viewed as placing the welfare of the one child over the other. This can be seen as placing the welfare of the sick child over the welfare of the “benefactor child” and could be viewed as an infringement of the “benefactor child’s” right to bodily integrity and section 28(2) of the Constitution. Again, this raises the question, where two children are involved, whose best interests are deemed to be more important?<sup>151</sup> As no answer exists in law, the same suggestion as made under the discussion on “saviour siblings” can be made here; that is, that the decision as to whether the proposed procedure takes place needs to be taken out of the hands of the parents and given to a neutral third party, such as a judge, with the assistance of a person such as the Family Advocate or ombudsman.

The approach, adopted by the court in the following Australian case of *Re GWW v CMW*,<sup>152</sup> may serve as a useful point of reference for South African

<sup>144</sup> S 56(2)(b) of the NHA.

<sup>145</sup> Ross, Thistlethwaite and the Committee on Bioethics “Minors as Living Solid-Organ Donors” 2008 *Pediatrics* 454 456.

<sup>146</sup> *Ibid.*

<sup>147</sup> Ross *et al* 2008 *Pediatrics* 456–457. See further ss 10 and 31 of the Children’s Act and art 12 of the UNCRC.

<sup>148</sup> The NHA gives every person, including children, the right to refuse treatment or surgery.

<sup>149</sup> Archard “Children’s Consent to Medical Treatment” in Ashcroft, Dawson, Draper and McMillan (eds) *Principles of Health Care Ethics* 2ed (2007) 311 312.

<sup>150</sup> Archard in Ashcroft *et al* (eds) in *Principles of Health Care Ethics* 315.

<sup>151</sup> The best interests of a child are of paramount importance in any matter. This is recognized by s 28(2) of the Constitution and s 7 of the Children’s Act.

<sup>152</sup> [1997] 21 Fam LR 612.

courts with respect to children under the legal age for consenting to medical treatment or surgery.

In this case, the Family Court sitting in Hobart had to decide whether the proposed medical procedure on a 10-year old child (B) in an attempt to save his maternal adult aunt (Mrs R), could be performed.<sup>153</sup> Mrs R suffered from leukaemia and required a bone-marrow transplant without which, her condition was terminal. Despite having her own young children as well as siblings and their spouses, it was only B who was a fully-matched relative donor to Mrs R. As the procedure to be performed was not for the benefit of B but for a third party, Hannon J considered it necessary that B be a party to the proceedings and that he be represented separately as well, thereby ensuring B's best interests were paramount at all times.

As this particular case concerned the bodily integrity of a minor, the court considered other cases of a similar nature as a reference point. One such case referred to was the British case of *Gillick v West Norfolk and Wisbech Health Authority*,<sup>154</sup> where it was held that a minor is capable of making a decision and consenting where there is sufficient understanding to fully understand what treatment is proposed. With this approach in mind, Mrs S a psychologist and expert witness testified that, although B understood what the procedure to remove bone-marrow involved, his depth of understanding was not sufficient enough to consent to the procedure himself. As such, B was not what is termed “Gillick Competent”. To be “Gillick Competent” means that a child has “sufficient understanding and intelligence to understand the nature and implication[s] of the proposed treatment” and can therefore consent to medical treatment.

Again, because this case dealt with the bodily integrity of a minor, the court had to determine whether this amounted to a case which fell outside the scope of parental consent. It had to be determined whether this was a special case and a matter that the court had to decide, as a wrong decision could have potentially grave consequences on a child's bodily integrity. It was decided that this was a special case and, therefore required an intervention by the court to protect the child.

In coming to a decision, Hannon J considered the opinion of the expert witness, the views of B's parents and the wishes of B.<sup>155</sup> Hannon J also considered what was ultimately in the best interests of B, as the best interests of a child are of paramount importance.<sup>156</sup>

The final decision of this case was that the procedure to remove bone marrow from B be authorized. Although this was a special case and the

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<sup>153</sup> B's parents tried on numerous occasions to dissuade B from wanting to help his aunt but were unsuccessful. It is submitted that, as B's parents felt differently to B, it was taken to the court to decide what would be in the best interests of B. The facts of this case can be found in general in Hocking and Ryrstedt in Hocking (ed) *The Nexus of Law and Biology: New Ethical Challenges* 9–11.

<sup>154</sup> 1986 AC 112 (HL).

<sup>155</sup> Despite their efforts to dissuade B, B indicated to his parents on numerous occasions, that he wanted to help his aunt.

<sup>156</sup> See s 28(2) of the Constitution.

ultimate decision was taken away from B's parents, they were authorized by Hannon J to consent to the procedure as well.<sup>157</sup>

Whether this is necessarily the best approach to be followed by the South African courts is unclear. This approach is questionable, as it does not address and factor in the weight of influence that a parent may have on a child's decision or opinion when it comes to donating tissue or organs. This approach does, however, provide some insight as to how the views and opinions of a child under the age of twelve must be considered, as well as how the courts can act as a neutral third party, acting in the best interests of the child.

## 6 RECOMMENDATIONS AND CONCLUSION

Recent scientific advances demand a careful consideration of legal and ethical issues. In this article, the focus of the discussion was on the legal implications associated with "saviour siblings" and "benefactor children" and what effect their purpose has on a child's right to bodily integrity and autonomy. Although not born for the same reasons, both "benefactor children" and "saviour siblings" serve the same purpose, which is to save the life of an ill sibling through the donation of tissue or organs.

Following the recent implementation of new law into the South African legal framework, children over the age of twelve are recognized as having the capacity to consent in their own right to medical treatment or surgery.<sup>158</sup> For those children under the age of twelve, their fate rests in the hands of their parents.<sup>159</sup> This is potentially problematic in those instances where parents are so emotionally burdened by the illness of one of their children, that they place the welfare of the sick child above that of the "benefactor child" or "saviour sibling". Whether this approach is correct is not clear, as the law does not stipulate which child's best interests are more important, the sick child or the "benefactor child"/"saviour sibling". Therefore, this is a matter that the courts will need to decide.

Furthermore, allowing parents to make the ultimate decision with regard to medical treatment and surgery potentially limits a child's rights to bodily integrity and autonomy. This is because the Constitution guarantees all persons the right to bodily integrity and, as children are guaranteed all Constitutional rights, they are theoretically entitled to decide and control what happens to their bodies.<sup>160</sup> However, children, especially young children (twelve years and younger), are considered to lack the maturity to make decisions of this nature.

To overcome these infringements, it is submitted that children under the age of twelve, (especially "benefactor children" and "saviour siblings") should be able either to participate in making the decision in regard to treatment or

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<sup>157</sup> See Hocking and Ryrstedt in Hocking (ed) *The Nexus of Law and Biology: New Ethical Challenges* 11.

<sup>158</sup> S 129(2) and (3) of the Children's Act.

<sup>159</sup> S 129(4) and (5) of the Children's Act.

<sup>160</sup> S 28(2) of the Constitution.

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surgery, or, make the decision with the assistance of an outside neutral third party (for example the court with the assistance of a person such as the Family Advocate or ombudsman). Furthermore, the combined approach of age and maturity used to determine capacity to consent, should be replaced by the mature approach. The mature approach recognizes that children do not develop at the same pace and does not unduly restrict the autonomy of children below twelve. Finally, a National Board similar to the HFEA in the United Kingdom should be established to review each proposed case of “saviour siblings”, thus ensuring that the embryo is treated with respect and that the welfare of “child to be” is a paramount consideration.

Presently, South African society has not been overwhelmed by the concept of “saviour siblings”, but there is evidence to suggest that “saviour siblings” could soon be making the move from Europe, North America and Australia to South Africa. With this in mind, South African lawmakers need to adopt a proactive approach and begin to draft and build on the legislation that is already in place. Whereas legislation pertaining to “saviour siblings” needs to be enacted or amended, current legislation already recognizes “benefactor children”.

No matter what the future of South African law may hold with regard to “benefactor children” and “saviour siblings”, it must be observed that:

“[p]arents may be free to become martyrs themselves. But it does not follow that they are free, in identical circumstances, to make martyrs of their children before they have reached the age of full and legal discretion when they can make that choice for themselves.”<sup>161</sup>

In summary, the recommendations listed below offer some possible solutions that could be implemented to address the identified problems.

- The first recommendation is that a National Board needs to be established, to review each proposed case of “saviour siblings”. The Board should consist of professionals in the fields of medicine and law. By establishing a Board, its members will be able to review and assess the reasons why parents want to create a “saviour sibling”. At the same time, a National Board will prevent parents from using the guise of wanting to have a “saviour sibling” to screen for embryos which are of the desired gender. Sex selection is strictly prohibited in international law and in the draft Regulations Regarding the Use of Human DNA, RNA, Cultured Cells, Stem Cells, Blastomeres, Polar Bodies, Embryos, Embryonic Tissue and Small Tissue Biopsies for Diagnostic Testing, Health Research and Therapeutics.

A National Board has been established in England, in terms of legislation. The Human Fertilisation and Embryology Authority is responsible for licensing amongst other things, the creation of “saviour siblings”. Since English legislation provides the most detailed provisions on “saviour siblings” and is the clearest, it is advisable that a similar approach be adopted in South Africa.

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<sup>161</sup> Rutledge J, *Prince v Massachusetts* 321 US 158 (1944).

- The second recommendation is that a neutral third party/ies needs to be assigned to matters where parents wish to remove tissue or organs from a “benefactor child” or “saviour sibling” in an effort to save a sick sibling. The law requires that the best interests of the child be of paramount importance in any matter, but it does not state how the test is to be applied when more than one child is involved and which child’s welfare is deemed to be more important. It was suggested that in highly emotive matters like this, the onus of decision making needs to be taken away from emotionally burdened parents and given to a neutral third party such as the court. As an impartial and unaffected party, a judge would be most suited to decide which child’s best interests are more important.

Additional third parties, such as a family advocate or ombudsman, must also be assigned to matters of this nature, as they will provide unbiased representation of the children. An ombudsman is an advocate for children’s rights and ensures that the rights and welfare of children are given full consideration as well as promoting the best interests of the child. In view of the fact that the office of the family advocate is very busy, it may be better for an office of the ombudsman to be established in South Africa at national level, as a designated ombudsman’s focus could be child-specific.

- The third recommendation is that a register with the names of “saviour siblings” needs to be drawn up. A register of “saviour siblings” will allow the National Board to monitor the welfare of “saviour siblings” and collect information that may be useful to future cases of “saviour siblings”, such as whether the initial techniques have had any effects later in life.
- The fourth recommendation can be viewed as a contentious issue, in that it would see the current combined approach for capacity to consent (age and maturity) being replaced by the mature approach. As it is not clear whether the age of twelve is necessarily the correct age for consenting to medical intervention, adopting a mature approach may be more readily welcomed. The mature approach would make provision for children who are deemed mature enough to consent to their own treatment or surgery. The mature approach is cognizant of the fact that children develop mentally, physically and emotionally at different stages. Adopting a mature approach would remove the threat of unduly stunting a child’s ability to judge and to make decisions for themselves.<sup>162</sup>
- The fifth recommendation relates to terminology. Certain sections of South African law fail to define key terms. As a result, the lack of definitions led to vagueness and ambiguity and a lack of clear understanding of the provisions which ultimately affected the application of the law. Terms that need to be defined by legislation include medical

<sup>162</sup> See Reynolds “Consent and Competence in Paediatrics” 2007 *International Journal of Children’s Rights* 504 as quoted in Kassan and Mahery “Special Child Protective Measures in the Children’s Act” in Boezaart (ed) *Child Law in South Africa* (2009) 214. See further *S v M supra* par 19 where it was held that “all children have the right to express themselves as independent social beings ... to themselves understand their bodies, minds and emotions and above all to learn ... and make choices in the wide social and moral world of adulthood”.

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treatment and surgical operations in section 129 of the Children’s Act. It was submitted that medical treatment is broad enough to include surgical operations. If this interpretation is to be accepted, it has potentially huge ramifications on parental consent. In other words, as medical treatment includes surgical operations, it will render the need for parental assistance by a child over twelve, null and void. The interpretation of medical treatment, however, has no bearing on whether a female child can consent to an abortion with or without parental consent. As was seen, section 129(1) of the Children’s Act states that the provisions of section 129 do not limit a child’s right to terminate a pregnancy.

Additional terms requiring clear definitions include medical and dental purposes in section 56 of the NHA. Although a regulation has been enacted, both the regulation and the NHA fail to define these terms, which has resulted in uncertainty as to the application of section 56.

- The sixth recommendation is that children need to be made more aware of their rights. As the provisions of the Children’s Act are new, they are not widely known and this means that children are presumably unaware of their rights. To overcome this problem, it is recommended that initiatives be undertaken to educate all children and adults on the rights of children. Article 42 of the UNCRC requires that children and adults be made aware of their rights and therefore the same approach must be adopted into national law.
- The final recommendation is that legislation regulating “saviour siblings” and other genetic research of this nature, should be enacted as soon as possible. The reason for such a recommendation is that law and science should develop at the same pace, to prevent law from becoming outdated. There is evidence to suggest that “saviour siblings” could be a part of South Africa’s short-term future, necessitating the implementation of appropriate law now, thereby preventing future uncertainty and loopholes in the law pertaining to “saviour siblings”.<sup>163</sup>

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<sup>163</sup> Swanepoel 2010 *THRHR* 2.