

Southern Cross Bioethics Institute  
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## Research Notes



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# Children's Human Rights to Natural Biological Origins and Family Structure

Margaret Somerville

*This paper by Margaret Somerville<sup>1</sup> was originally presented at the Symposium on the Jurisprudence of the Family at Bratislava Law School in May 28-29, 2010 and published in the International Journal of Jurisprudence of the Family.*

## Abstract

Over the millennia of human history, the idea that children—at least those born into a marriage—had rights with respect to their biological parents was taken for granted and reflected in law and public policy. But with same-sex marriage, which gives same-sex spouses the right to found a family, that is no longer the case.

Likewise, children's rights with respect to their biological origins were not an issue when there was no technoscience that could be used to manipulate or change those origins: a baby could only be conceived in vivo through sexual reproduction. But with assisted human reproductive technologies (ARTs) and genetic technologies, that, too, is no longer the case.

So, in light of these new realities, what are our obligations, as societies, to children with respect to their biological origins and biological families? What protections do children need and deserve?

I propose that the most fundamental human right of all is a child's right to be born from natural human biological origins and that children also have human rights with respect to knowing who

their biological parents and families are, and that these rights must be recognized. Children also have a right to be reared within their biological families and to have a mother and a father, unless an exception can be justified as being in the 'best interests' of a particular child.

The connection among adoption, the use of new reproductive technologies, and same-sex marriage is that they all unlink child-parent biological bonds. Each context raises one or more of three important issues: children's right to know the identities of their biological parents; children's right to both a mother and a father, preferably their own biological parents; and children's right to come into being with genetic origins that have not been tampered with; that is, 'designing' our children should be prohibited.

Such 'designing' would result in losses with implications far beyond those persons directly affected and far beyond the present time. It would undermine the rights to equality and freedom of future generations. Because the liberty and equality of all citizens is at the heart of democratic societal institutions and of the values that democratic societies promote, to create people who are neither free nor equal undermines those institutions and values. In short, not to prohibit 'designer children' would undermine the very foundations of our Western democratic societies.

## Introduction

Some old and new phenomena—adoption is old, assisted reproductive and genetic technologies and same-sex marriage are new—have recently thrown the issue of children's rights with respect to their biological origins, biological families, and family structure into the public policy spotlight and public square debate.

Adoption has long given rise to concerns as to children's rights with respect to their biological families. Early in the twentieth century, societally condoned sperm donation presented a similar challenge. In the last thirty years, assisted

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reproductive technologies (ARTs) and genetic technologies have brought, and will continue to bring, unprecedented challenges. And, most recently, same-sex marriage has done so.

The connection among these contexts is that they all unlink child-parent biological bonds.<sup>2</sup> Each context raises one or more of three important issues: children's right to come into being with genetic origins that have not been tampered with; children's right to know the identities of their biological parents; and children's right to both a mother and a father, preferably their own biological parents.

Over the millennia of human history, the idea that children—at least those born into a marriage—had rights with respect to their biological parents was taken for granted and reflected in law and public policy. And children's rights with respect to their biological origins were not an issue when there was no technoscience that could be used to manipulate or change those origins: a baby could only be conceived in vivo through sexual reproduction. But with ARTs that is no longer the case.

What, ethically, do we owe children whose lives result from the use of ARTs? So far, we have largely failed to address this question. Our ethical focus on ARTs has been almost entirely on adults' right to access these technologies so as to found a family. But as the first cohort of children born as a result of their use reaches adulthood and connect with one another through the Internet, they are changing our focus. We are now asking, what are their rights with respect to their biological origins and biological families? And what are our obligations as a society to these children? What protections do they need and deserve?

In this article, I propose that the most fundamental human right of all is a child's right to be born from natural biological origins, that children have human rights with respect to their biological parents and families, and that these rights must be recognized. The articulation of human rights is an ongoing process. Children must move from being the 'voiceless citizens' to becoming the new kids on the human rights block, and nowhere is

that more important than with respect to rights regarding their biological origins and biological families.

## I. Children's Right to Be Born from Natural Biological Origins

In the more than twenty-five years since Louise Brown, the first 'test-tube baby', ushered in the brave new world opened up by ARTs, advances in the technologies have made more and more previously impossible interventions possible. Those 'advances' make it necessary to formulate new rights for children in relation to their biological origins that would have been unimaginable until very recently.

A child's right to be conceived with a natural biological heritage is the most fundamental human right and should be recognized in law.<sup>3</sup> Children have a right to be conceived from untampered-with biological origins, a right to be conceived from a natural sperm from one identified, living, adult man and a natural ovum from one identified, living, adult woman. Society should not be complicit in—that is, should not approve or fund—any procedure for the creation of a child, unless the procedure is consistent with the child's right to a natural biological heritage.

The addition of the words *man* and *woman* in defining the right to a natural biological heritage, rather than simply referring to sperm and ovum, as would be more common, is not superfluous. It is theoretically possible to create an embryo with the genetic heritage of two women or two men, including by making a sperm or ovum from one of the adult's stem cells and using a natural gamete from the other person, or perhaps by using two ova or maybe by making an 'ovum' from an enucleated egg fused with a sperm and fertilizing it with another sperm. The word *natural* excludes opposite-sex couples from using this technology to make an artificial sperm from an infertile man or artificial ovum from an infertile woman.

The requirement that the gametes come from adults preempts the use of gametes from aborted fetuses; it prevents children being born whose biological parent was never born. And the requirement that the donors be living excludes the use

<sup>2</sup> Margaret Somerville, *Children's Rights and Unlinking Child-Parent Biological Bonds with Adoption, Same-Sex Marriage and New Reproductive Technologies*, 13 *J. FAM. STUD.* 179 (2007).

<sup>3</sup> MARGARET SOMERVILLE, *THE ETHICAL IMAGINATION: JOURNEYS OF THE HUMAN SPIRIT* 95–156 (2006); Margaret Somerville, *The Importance of a Basic Presumption of Respect for the Natural*, 13 *SACRED WEB: A J. OF TRADITION AND MODERNITY* 113 (2004).



of gametes for postmortem conception. The right to bear children should not include the right to deny children at least the chance, when being conceived, of meeting their biological parents. Conceiving children with gametes from a dead donor, as an Australian court authorized,<sup>4</sup> denies them this opportunity. In that case, as is so often true, the judge considered only the rights and wishes of the adults involved.

## II. 'Designer Children' and Societal Values and Institutions

A topic linked to the previous one of a right to come from untampered-with human origins, is the ethical acceptability of the enhancement of one's children using genetic technologies. The central question raised is whether or not this offends human dignity, whether of the child as an individual or of humans in general. Some commentators argue it does and others that it does not. I will not explore, here, however, the extensive literature on the ethics of designing our children by genetically altering them, whether for the better or the worse—when they are embryos. Rather, I want just to mention some important philosophically based objections to doing that, which have not been widely discussed.

Because creating 'designer children' involves genetic manipulation of human embryos, it destroys the essence of their humanness and, ultimately, the essence of the humanness of all of us.<sup>5</sup> Genetic manipulation interferes with the intrinsic being of a person—with their very 'self'. As philosopher Søren Kierkegaard put it, designed persons are not free to fully become themselves, which is the essence of freedom.<sup>6</sup>

The power to fully become oneself requires that the person has non-contingent origins. People need to have a sense that they can go back and start again to remake or actualize their very selves, and, in order to have that, they must not be preprogrammed or designed by another. German philosopher Jürgen Habermas<sup>7</sup> agrees that designed persons no longer can own them-

selves, as they must do in order to make their beings and their lives fully their own. Lacking self-ownership, people are not fully free. They are deprived of the liberty that comes from the fact that no one has interfered with the essence of their being. This lack of interference means their genetic makeup has come into existence through chance, and that it do so in that way is a necessary condition for such liberty. Moreover, because these children are not equal to the designer, they are deprived of equality.

This loss of liberty and equality affects the humanness of all of us because, first, we would all be complicit in such manipulation by not prohibiting it. And second, as Habermas explains, because tampering with some people's origins destroys a necessary condition for establishing a moral base for a secular society—that all people must be free from others' interference in their intrinsic being if they are to have the capacity to take part in the human interaction from which a shared morality arises.<sup>8</sup>

The injustice of one generation imposing its will over another generation (if the first generation designs its own children) would also result in other losses that have implications far beyond those people directly interfered with and the present time. The use of these technologies by one generation challenges the basic human rights of equality and freedom of future generations. And because the liberty and equality of all citizens is at the heart of democratic societal institutions and of the values which democratic societies promote, to create people who are neither free nor equal undermines those institutions and values. In short, not prohibiting 'designer children' undermines the very foundations of our Western democratic societies.

## III. Children's Rights and Donor Conception

We must explore two lines of enquiry in relation to children's rights and donor conception: Is donor conception ethically acceptable? And, if so, under what conditions, in particular, do children have a right to know the identities of their gamete donors?

4 Richard Kerjab, *Wife Gets Sperm of Dead Husband*, *THE AUSTRALIAN*, December 21, 2005, at 3.

5 MARGARET SOMERVILLE, *supra*, notes 2 and 3.

6 SØREN KIERKEGAARD, *EITHER/OR*, PART 2 (Howard V. Hong & Edna H. Hong, eds. & trans.) In *4 KIERKEGAARD'S WRITINGS* (Howard V. Hong, ed., 1987), as cited in Habermas, *infra*, note 7, at 5–11.

7 JÜRGEN HABERMAS, *THE FUTURE OF HUMAN NATURE*, 53–66 (2003).

8 *Id.*

## Is Donor Conception Ethically Acceptable?

Many people have come to see gamete donation and donor conception as acceptable for opposite-sex couples who do not regard it as immoral. But, as I discuss below, some donor-conceived people adamantly disagree. Whether it should be available to same-sex couples or single women is a much more contentious issue. It merits noting in this regard that some sperm banks report that more than half of the women who use their services are single.<sup>9</sup> It's also worth noting that the use of artificial insemination can be reduced by prohibiting the sale of sperm or preventing the donors from remaining anonymous. Many men would refuse to donate if they would not be compensated or if their paternity might become known.

The emphasis in the ethical and legal analysis of the use of ARTs, including donor conception, has been on the rights and wishes of the adults involved - for instance, the gamete donors or prospective "parents". Some donor-conceived people strongly object to this approach. They argue that the rights and well-being of children born through the use of these technologies must be central to decision-making, which could mean that some of these technologies should not be used at all. .

The impact of ARTs, including donor conception, on children born through their use, other than that on their physical health, has been largely ignored; it has been readily assumed that no major ethical or other problems arise in creating children from donated gametes, and that opposition to the creation of these children is almost entirely based on religious beliefs. Such assumptions have been dramatically challenged in the last few years as the people in the first cohort born through the use of these technologies reach adulthood, become activists, and call for change. They describe powerful feelings of loss of identity through not knowing one or both biological parents and their wider biological families, and

describe themselves as 'genetic orphans'.<sup>10</sup> They ask, 'How could anyone think they had the right to do this to me?'

It merits keeping in mind in this discussion that we are speaking of a very large number of people who could believe they have been harmed in these ways. Although precise numbers do not exist, it's estimated that in the United States, alone, 30,000 to 60,000 children are born each year through sperm donation<sup>11</sup> and, in 2005, about 6,000 babies were born from ova donation.<sup>12</sup> It is also not irrelevant to this discussion that in America the fertility industry brings in \$3.3 billion annually.<sup>13</sup>

A common strategy used to dismiss the arguments against donor conception is that there is no 'proof' that donor-conceived persons, either as children or later, as adults, are harmed in any important way. Studies carried out on young donor-conceived children, who declare themselves perfectly happy with their parents and families, are often put forward as evidence that no harm is caused. In contrast, donor-conceived adults' claims of identity confusion, loss of connection to half their genetic kin, psychological distress, and so on, tend to be dismissed as anecdotal and irrelevant, and they are challenged to prove empirically the harm done to them.

But that is to ask the impossible. Sociology is not hard science, and qualitative research can indeed be a valid way to proceed. In addition, it's very difficult to find a large random sample of donor-conceived people: most parents never tell their children about their origins. Moreover, this secrecy is itself likely to cause harm to many donor-conceived people, but it is impossible to study that either.

Studies on young donor-conceived children, which purport to show there is no harm, do not capture harms experienced only later. For

9 Jessica Yadegaran, *No Mr. Right? More Women Start Families via Artificial Insemination*, *CONTRA COSTA TIMES*, August 16, 2010, available at

<http://www.parentcentral.ca/parent/babiespregnancy/pregnancy/article/848516--no-mr-right-more-women-start-families-via-artificial-insemination> (accessed October 1, 2010).

10 See Chad Skelton, *Searching for Their Genes: Family Ties*, *VANCOUVER SUN*, April 22, 2006.

11 Elizabeth Marquardt, Norval D. Glenn & Karen Clark, *My Daddy's Name is Donor 5*, Institute for American Values (2010), available at [http://www.familyscholars.org/assets/Donor\\_FINAL.pdf](http://www.familyscholars.org/assets/Donor_FINAL.pdf)

12 *Id.*, at 17.

13 *Id.*, at 5.

instance, in early adulthood, when we are forming a mature self-identity, knowing our origins and biological family helps us to find that identity.<sup>14</sup>

The ethical doctrine of anticipated consent is relevant in deciding what we owe ethically to children brought into being through ARTs, including donor conception. Anticipated consent requires that when a person seriously affected by a decision cannot give consent, we must ask whether we can reasonably anticipate they would consent if able to do so. If not, it's unethical to proceed. So, ethically, we must listen to what donor-conceived adults are saying about gamete donation to decide whether we can anticipate consent to it.

They—like adopted children—tell us of their profound sense of loss of genetic identity and connection. They wonder: Do I have siblings or cousins? Who are they? What are they like? Are they 'like me'? What could I learn about myself from them? These questions raise the issue of how our blood relatives help each of us to establish our human identity.<sup>15</sup> Humans identify closely with their close genetic families, and it seems that we also identify with traits in our family members that we like (we try to develop the same traits in ourselves), and that we dislike (we vow not to be like that—the positive power of negative identification).<sup>16</sup> In short, from what many donor-conceived adults tell us we cannot anticipate consent to anonymous gamete donation—or, indeed, to gamete donation itself.

Two stories concerning the donation of gametes that raise additional questions have appeared recently in the media. One related that a 'virtual' sperm and egg bank is being established that will only accept offers to donate from 'beautiful' people. Internet polling will determine who is sufficiently beautiful. The goal—informed by the principle that 'everyone deserves a beautiful

child'—is to enable 'ugly' people to have beautiful children.<sup>17</sup> If we tack on surrogate motherhood to this 'service,' a person could order a custom-made child and collect it nine months later.

The other story reported that New Zealand will possibly allow 'double donation'; that is, would-be parents would be able to use both donated ova and sperm to create embryos (a practice that is not legally prohibited, although still fairly uncommon, in Canada). As Diane Allen of the Infertility Network argues, this 'cannot be construed as any form of infertility "treatment", but, rather, the deliberate manufacture of babies to meet consumer demand'.<sup>18</sup>

Donor conception may be a completely avoidable human tragedy in the making, one for which we might be holding a truth and reconciliation commission at some future date, when offspring ask, as some are already doing, 'How could you have done this to us? How could you have allowed this to happen?'

Is donor conception the twenty-first century version of the wrongs we now recognize we did to some children in the twentieth century? Are we repeating in a new context and in new ways the terrible errors and grave injustices that occurred with Australia's 'stolen generation' of aboriginal children, the United Kingdom's 'home children' sent to Canada and other British Commonwealth countries, and the 'scoop' of native children from reserves into Canadian residential schools and white adoptive homes, all of which deliberately separated children from their biological families?

In all these instances, our intentions were, just as our intentions are at present in regards to donor conception, to 'do good'. In donor conception, however, we primarily intend to 'do good' to the adults who want a child, rather than to the child; whereas in the instances of the other historical wrongs I have mentioned, the perpetrators sometimes acted out of the belief—although a grossly mistaken belief—that their policies were good for the children. As an old human-rights axiom

14 See David J. Vellaman, *Family History*, 34 *PHIL. PAPERS* 357 (2005).

15 See generally T. Freeman, V. Jadva, W. Kramer & S. Golombok, *Gamete Donation: Parents' Experiences of Searching for their Child's Donor Siblings and Donor*, 1 *Human Reproduction* 1 (2009), especially at pages 7–9, where it is reported that children were usually positively affected by meeting siblings and that close bonding often resulted. Available at <http://www.oxfordjournals.org/eshre/press-release/freepdf/den469.pdf> (accessed September 10, 2010).

16 David J. Vellaman, *supra*, note 14; ELIZABETH MARQUARDT ET AL., *supra*, note 11.

17 *Dating Site Creates Online Sperm and Egg Bank*, *Newsweek*, available at <http://www.newsweek.com/blogs/techtonic-shifts/2010/06/21/dating-site-creates-online-sperm-and-egg-bank.html> (accessed September 30, 2010). The dating site is BeautifulPeople.com

18 Personal email communication from Diane Allen, *Infertility Network*, to Margaret Somerville, June 28, 2010.

warns, an unalloyed intention to 'do good' has its dangers: 'Nowhere are human rights more threatened than when we act purporting to do only good'. Our desire to do good can blind us to the risks and harms that are involved. Is that true of gamete donation?

An argument that is used to support donor conception is that the child would not exist otherwise and, therefore, should not complain. One young donor-conceived woman, confronted with this argument, responded, 'If I were the result of rape, I would still be glad to be alive, but that doesn't mean I or anyone else should approve of rape.'

### **Children's Right to Know the Identities of their Biological Parents**

If, however, the practice of donor conception continues, what are our obligations to people conceived in this way with respect to giving them access to information about their biological origins?

It is one matter for children not to know their genetic identities as a result of unintended circumstances. It is quite another matter to deliberately destroy children's links to their biological parents, and especially for society to be complicit in this destruction. It is now being widely recognized that adopted children have the right to know who their biological parents are whenever possible, and legislation establishing that right has become the norm. The same right is increasingly being accorded to children born through gamete donation. For instance, the United Kingdom has passed laws giving children conceived after April 1, 2005, this right at 18 years of age.<sup>19</sup>

<sup>19</sup> *Human Fertilisation and Embryology Act, ch. 22, § 24 (2008), amending § 31 of the 1990 Act, by adding section 31ZA. The act provides that donor-conceived people conceived after April 1, 2005, when they reach 16 years old, are able to apply to the HFEA to receive the non-identifying information that their donor provided (all information given by the donor except for his or her name and last-known address). Donor-conceived people conceived after April 1, 2005, when they reach 18 years old, are able to apply to find the information their donor provided, including identifying information. Note that it is only non-identifying donor information that can be provided at age 16. In order to get identifying information, donor-conceived people have to wait until they are 18.*

Ethics, human rights, and international law<sup>20</sup>—as well as considerations such as the health and well-being of adopted and donor-conceived children—all require that children have access to information regarding their biological parents. And it is not just these children who have this right, but their descendants as well. Children deprived of knowledge of their genetic identities—and their descendants—are harmed physically and psychologically.

If donor conception continues, respect for children's rights in these regards requires that the law prohibit anonymous sperm and ova donation, establish a donor registry, and recognize children's rights to know the identities of their biological parents and, thereby, their own biological identities.

Adoption is our longest-standing experience of dealing with a situation where children have been intentionally disconnected from their biological parents and, often, did not know and could not find out who their biological parents and relatives were. In the past, adoption records were permanently sealed. We now recognize that as being harmful to the adopted person and potentially to the birth family, and unethical. Yet donor-conceived Canadians do not know who at least one of their biological parents is, because donors in Canada are allowed to remain anonymous, which is no longer the case in a growing list of countries (including Britain, Australia, and New Zealand, among many others<sup>21</sup>). That also is unethical and, if we continue with gamete donation, it must be changed.

Adoptive parents were once advised by 'professionals'—as the parents of donor-conceived children have been and still often are—not to tell their children of their origins; they were told that secrecy was best. This, too, should be changed, not least because people excluded from a secret that relates to them in some major way often sense that they are being excluded. Their not knowing what the secret is creates a situation of doubt, which can be very difficult for them to cope with psychologically. Moreover, such secrets

<sup>20</sup> **Convention on the Rights of the Child, GAOR 44/25, annex, 44 U.N. GAOR Supp. (No. 49) at 167, U.N. Doc. A/44/49 (1989), entered into force Sept. 2, 1990, available at <http://www1.umn.edu/humanrts/instrree/k2crc.htm>**

<sup>21</sup> *MARQUARDT ET AL., supra, note 11, at 77.*



can damage—sometimes even destroy—family relationships once they come to light, as most inevitably do, often in traumatic situations (for example, divorce or death).

Adoptive parents were also told that children were a blank slate, that they would be just fine and would not experience loss because of their adoptive family loving them, really ‘wanting them’, ‘going through so much to get them’, and so on. For many adopted children, even those who deeply love their adoptive parents, this has not proven to be true, as is also the case for some donor-conceived children. Now, prospective adoptive parents are counselled during the home-study process to expect and accept this sense of loss as normal.

Birth parents were told—as gamete donors are today—that it was in their own best interests to ‘put it behind them and get on with their lives’, that their relinquished children would be just fine, that they were doing a ‘wonderful, selfless’ thing in helping people become parents who couldn’t otherwise do so. But this ‘moving on’ was not always possible for the birth parents, as is also true for some gamete donors.

### **The Ethical Way Forward**

I suggest that the first step in dealing, ethically, with the issues I have identified in this section, and with other related issues, is to place the future child, and the child’s human rights and our obligations as a society to him or her, at the centre of the decision-making as to what should be required, allowed, or prohibited—that is, what we must, may, or must not do, respectively—in the use of assisted human reproduction technologies, including gamete donation.

The child cannot tell us what he or she would consent to, but other people conceived in these ways can. As I’ve explained already, we must listen to them in order to apply the ethical doctrine of ‘anticipated consent’; that is, if we cannot reasonably assume that someone affected by our decision, who is not present, would consent if present, it is not ethical to proceed.

The ‘precautionary principle’, currently most commonly used in environmental ethics, might also help: we should exercise wise ethical restraint—prudence—until we are reasonably certain that it is safe and ethical to act. And that

safety goes beyond assessing only physical harm to the future child. It also includes taking into account existential harm to him or her, and risk and harm to our societal values and ethics.

What impact, especially on important values on which we found our shared societal ethics, would wanting only beautiful children have on our concept of unconditional parental love? Hitherto, we have believed we love our children simply because they are our children. Does the selection and purchase of gametes to conceive a child make the child into an object or thing, rather than a person? How will the child feel knowing that a genetic parent sold what is (as one donor-conceived woman put it) ‘the essence of my life for \$25 to a total stranger, and then walked away without a second look back? What kind of a man sells himself and his child so cheaply and so easily?’ Is there something gravely ethically wrong with the commercialization of the miracle of the passing on of human life? Canadians decided there was, and that leads to yet another recent donor-conception news story.

In 2005, the Canadian Parliament enacted the Assisted Human Reproduction Act that made it a criminal offence to buy or sell gametes or embryos.<sup>22</sup> Assisted Human Reproduction Canada—the agency that was established to oversee the implementation of this statute—has just been challenged with allegations it is failing to fulfill its obligations by not seeking prosecution of those who take part in the continuing sale of sperm and ova in Canada.<sup>23</sup>

### **IV. Children’s Right to Be Reared within Their Own Biological Families**

The general norm or default position in Western societies has long been that parents have obligations to care for their biological children, at least those born into a marriage. In more recent times those obligations have extended to all their biological children. That means that children have correlative rights with respect to their biological parents and family structure. As adoption law impliedly recognizes, a child has a right to be in

<sup>22</sup> *Assisted Human Reproduction Act*, ch. 2, § 7 (2004).

<sup>23</sup> Tom Blackwell, *Third Board Member Quits Fertility Industry Watchdog*, National Post, May 31, 2010, available at <http://www.nationalpost.com/news/story.html?id=3094251#ixzz117FaV0xL> (accessed October 1, 2010).

contact with his or her biological parents within a family structure—that is, to be reared by their biological mother and father within their genetic family—unless an exception is unavoidable in the ‘best interests’ of a particular child. In short, adoption can be viewed as a default position where neither the biological mother nor father is capable of adequately parenting the child.

It might be objected that there is no magic in biological matching. It might also be supposed that genetically controlled development and environmentally determined development run on entirely different tracks, so that the suitability of a couple to parent a particular child can be determined with little reference (except perhaps in exceptional cases such as those presented by special-needs children) to the genetic structure of the child, and still less reference to some sort of matching between the genetic structure of the couple and that of the child. This conclusion might have been unchallenged orthodoxy until recently. However, scientific research is giving us possible clues to the contrary. This research indicates that when we mess around with Nature in the context of human reproduction, we may have no idea of all the implications of what we are doing. Let me briefly refer to just two examples.

Research is showing that smell can indicate whether an opposite-sex partner is more or less genetically compatible in relation to reproduction: women who are not pregnant find the smell of men who are ‘immunologically dissimilar’ from them—that is, men who are likely to have genomes different from their own—more attractive than the smell of men with similar genomes. Genetic difference between the parents increases the likelihood of more immunologically robust offspring.<sup>24</sup> Such studies raise interesting questions about the desirability of having parents who have selected one another the old-fashioned way, rather than through the impersonal mechanisms of artificial insemination by donor or ovum donation. They also raise questions about the advisability of women who are taking oral contra-

ceptives, which affect pheromones and the sense of smell, selecting partners for marriage or with whom to reproduce.

And a breakthrough in a new field of scientific research called ‘epigenetics’,<sup>25</sup> which investigates the interaction of genes and environment, breaches the barrier between environment and genetics by revealing that some genes are imprinted—‘activated’—by parenting practices<sup>26</sup> and other environmental factors (and that epigenetic changes can be passed on to future generations, including through the behaviour of the parents).

It may emerge, therefore, that the optimal parenting practices for a child depend in part on that child’s genetic inheritance—the child’s genome or DNA/RNA—and its amenability to activation by one or another set of parenting practices. Good parenting for one child might be mediocre parenting or worse for another depending on their genomes. A further insight that might emerge is that parenting practices themselves are in part a product of genetics and

24 Suma Jacob, Martha K. McClintock, Bethanne Zelano & Carole Ober, *Paternally Inherited HLA Alleles Are Associated with Women’s Choice of Male Odor*, 30 *NATURE GENETICS* 175 (2002); Karl Grammer, Bernhard Fink & Nick Neave, *Human Pheromones and Sexual Attraction*, 118 *EUR. J. OBSTETRICS & GYNECOLOGY & REPRODUCTIVE BIOLOGY* 135 (2005).

25 *Epigenetics refers to functionally relevant modifications to the genome that do not involve a change in nucleotide sequence. Such modifications include chemical marks that regulate the transcription of the genome. There is now evidence that environmental events can directly modify the epigenetic state of the genome. Thus studies with rodent models suggest that during both early development and in adult life, environmental signals can activate intracellular pathways that directly remodel the ‘epigenome’, leading to changes in gene expression and neural function. These studies define a biological basis for the interplay between environmental signals and the genome in the regulation of individual differences in behavior, cognition, and physiology.* Tie-Yuan Zhang & Michael J. Meaney, *Epigenetics and the Environmental Regulation of the Genome and Its Function*, 61 *Ann. Rev. Psych.* 439 (2010), available at [http://www.annualreviews.org/doi/abs/10.1146/annurev.psych.60.110707.163625?url\\_ver=Z39.88-2003&rfr\\_dat=cr\\_pub%3Dncbi.nlm.nih.gov&rfr\\_id=ori%3Arid%3Acrossref.org&journalCode=psych](http://www.annualreviews.org/doi/abs/10.1146/annurev.psych.60.110707.163625?url_ver=Z39.88-2003&rfr_dat=cr_pub%3Dncbi.nlm.nih.gov&rfr_id=ori%3Arid%3Acrossref.org&journalCode=psych) (accessed September 12, 2010).

26 Ian C. G. Weaver, Nadia Cervoni, Fances A. Champagne, Ana C. D’Alessio, Shakti Sharma, Jonathan R. Secki, Sergiy Dymov, Moshe Szyf, & Michael J. Meaney, *Epigenetic Programming by Maternal Behavior*. 7 *Nature Neuroscience* 847 (2004), available at <http://www.nature.com/neuro/journal/v7/n8/full/nn1276.html> (accessed September 11, 2010). The extensive debate which has ensued from this well-known study is reviewed in Lizzie Buchen, *Neuroscience: In their nurture*, 467 *Nature* 146 (2010), available at [http://www.nature.com/news/2010/100908/full/467146a.html?s=news\\_rss&utm\\_source=feedburner&utm\\_medium=feed&utm\\_campaign=Feed%3A+news%2Frss%2Fmost\\_recent+\(NatureNews++Most+recent+articles\)#B3](http://www.nature.com/news/2010/100908/full/467146a.html?s=news_rss&utm_source=feedburner&utm_medium=feed&utm_campaign=Feed%3A+news%2Frss%2Fmost_recent+(NatureNews++Most+recent+articles)#B3) (accessed September 11, 2010).

epigenetics, and that biological parents may be more likely to be matched by nature in such a way as to lead their parenting behavior to be optimal for their own biological offspring. Confirmation of these possible outcomes must await further research.<sup>27</sup> I hasten to add that in articulating these possibilities I am not endorsing 'genetic reductionism', the claim that we humans are nothing more than the functioning of our genes or 'gene machines'.

This new knowledge also gives rise to questions about criteria for adoption. It raises the question whether there should be a presumption, subject to an exception, where an exception would be in the 'best interests' of a particular child, that children should be adopted by couples comprised of a man and a woman.

## V. Children's Right to Both a Mother and a Father

And that enquiry brings us to the issue of same-sex marriage, which has been legalized in Canada<sup>28</sup> and some other countries. Under both article 16 of the U.N.'s Universal Declaration of Human Rights<sup>29</sup> and domestic law, marriage is a compound right: the right to marry and to found a family.

Giving same-sex couples the right to found a family unlinks parenthood from biology. In doing so, it unavoidably takes away all children's right—not just those brought into same-sex marriages—to both a mother and a father and their right to know and be reared within their own biological family. It does so because marriage can no longer establish as the norm the natural, inherently procreative relationship between a man and a woman and the rights of children that flow from that norm: in particular, the right of children to both a mother and a father who are their own

biological parents, unless an exception is justified as in the 'best interests' of a particular child, as in adoption.

The primary rule becomes that a child's parents are who the law says they are, and they may or may not be the child's biological parents.<sup>30</sup> That is, the exception to biological parenthood, which used to be allowed through adoption law, becomes the norm. In other words, same-sex marriage radically changes the primary basis of parenthood from natural or biological parenthood to legal (and social) parenthood as the Canadian Civil Marriage Act expressly legislates.<sup>31</sup> That change has major impact on the societal norms, symbols, and values associated with parenthood.

The same issue of children's right to both a mother and a father is raised by society's involvement in intentionally creating single-parent households, for example, by funding single women's access to artificial insemination, which has been discussed above.

Same-sex marriage advocates argue that children don't need both a mother and a father, and 'genderless parenting' is just as good as, or even better than, opposite-sex parenting, because in the case of same-sex couples, all children are wanted children. Research is showing, however, that men and women parent differently<sup>32</sup> and, as I've already explained, other research in epigenetics shows that certain genes in young mammals are activated by parental behaviour. Science may well show us that complementarity in parenting (having both a mother and a father)

27 I am indebted to Professor Scott FitzGibbon for suggesting the arguments related to epigenetics presented here.

28 Civil Marriage Act, R.S.C. 2005, ch.33.

29 Universal Declaration of Human Rights, GAOR 217A (III), U.N. Doc. A/810 (1948), adopted December 10, 1948, available in the University of Minnesota Human Rights Library: <http://www1.umn.edu/humanrts/instrree/bludhr.htm> (accessed September 11, 2010). Article 16(1) provides: 'Men and women of full age, without any limitation due to race, nationality or religion, have the right to marry and to found a family.'

30 See the very recent British Columbia White Paper on Family Act Reform, available at <http://www.ag.gov.bc.ca/legislation/pdf/Family-Law-White-Paper.pdf> See also Todd Coyne, *New BC family law could legalize having three parents*, Vancouver Sun, July 19, 2010, available at <http://www.vancouversun.com/life/family+could+legalize+having+three+parents/3297731/story.html>

31 Civil Marriage Act, *supra*, n. 38, Consequential Amendments §§ 5–15. For example, the amendment to the Income Tax Act states: 'The amendments to sections 56.1 and 60.1 of the Act replace the existing term 'natural parent' with the term 'legal parent' to ensure that support amounts paid under a court order or written agreement involving both opposite-sex and same-sex couples and their children will be recognized equally in federal law' (emphasis added).

32 See, for example, Gordon et al., *Oxytocin and the Development of Parenting in Humans*, 68 *BIOLOGICAL PSYCHIATRY* 377 (2010), in which the author identifies disparate parenting conduct, which is a function of oxytocins.

does matter for children's well-being in ways we have not previously understood. In short, mothers and fathers parent differently and, therefore, it would seem, confer different benefits on the child.

Two further considerations also need to be taken into account. They both rest on one prominent school of child-development thought which emphasizes that children develop through a process of 'modelling'.<sup>33</sup>

The first consideration is that a boy needs an adult male parent on whom to model himself and a girl an adult female parent; a same-sex couple will, therefore, fall short with either the male or the female children. The second consideration looks to the relationship between the parents: children benefit when they can model their own relationships with the opposite sex, in later life, on the relationship conducted by their parents.<sup>34</sup>

One argument against same-sex marriage raised in the Canadian court cases was that same-sex couples could not found a family naturally and, therefore, marriage was not an appropriate way to publicly recognize their committed relationship. The Court of Appeal of Ontario<sup>35</sup> responded, however, that these couples could use reproductive technologies to found a family. The common thread between same-sex marriage and repro-

ductive technologies is that both disconnect procreation from sexual intimacy between two humans: same-sex marriage involves sexual intimacy with no possibility of procreation; reproductive technologies involve procreation with no sexual intimacy.

The debate on legalizing same-sex marriage in Canada focused almost entirely on adults and their right not to be discriminated against on the basis of their sexual orientation. The conflicting claims, rights, and needs of children were barely mentioned. It's worth noting that legally recognizing civil unions, unlike the recognition of same-sex marriage, does not negate children's right to both a mother and a father, because it does not include the right to found a family. For that reason, I believe it represents the most ethical compromise between respect for the rights of homosexual people not to be discriminated against and the rights of children with respect to their biological families.

## VI. Conclusion

All these rights of children are of the same basic ethical nature—obligations of non-maleficence, that is, obligations to *first do no harm*. Consequently, as a society, we have obligations to ensure respect for these rights of children. It is one matter, ethically, not to interfere with people's rights of privacy and self-determination, especially in an area as intimate and personal as reproduction. It is quite another matter for society to become complicit in intentionally depriving children of their right to know and have contact with their biological parents and wider family, or their right to be born from natural biological origins. When society approves or funds procedures that breach these rights of children and, arguably, when it fails to protect such rights of children—for instance, by failing to enact protective legislation—society becomes complicit in the breaches of rights that ensue.

Those obligations extend also to future generations. We should clearly recognize that any genetic procedure that will turn out to be harmful to the future child or to a future generation, or contrary to their interests, is morally unacceptable and should be prohibited.

33 Gareth B. Matthews, *Concept Formation and Moral Development*. In *PHILOSOPHICAL PERSPECTIVES ON DEVELOPMENTAL PSYCHOLOGY* 175, at 185 (James Russell ed., 1987) ('A young child is able to latch onto the moral kind, bravery, or lying, by grasping central paradigms of that kind. . . . Moral development is . . . something much more complicated than simple concept displacement. It is: enlarging the stock of paradigms . . . developing better and better definitions of whatever it is that these paradigms exemplify; appreciating better the relation between straightforward instances of the kind and close relatives; and learning to adjudicate competing claims from different moral kinds . . .'). See also Lawrence J. Walker, Karl H. Hennig & Tobias Krettenauer, *Parent and Peer Contexts for Children's Moral Reasoning Development*, 71 *CHILD DEV.* 1033, 1047 (2000) (reporting that both parents and peers 'have a role to play'). See generally A. Bandura, *Social Cognitive Theory: An Agentic Perspective*, 52 *ANN. REV. PSYCHOL.* 1 (2001).

34 Scott FitzGibbon, *Procreative Justice and the Recognition of Marriage*. In *Family Law in the 21st Century*, pp.1006 (M. Obi & K. Nijijima, eds., 2007), available at <http://lawdigital-commons.bc.edu/lsp/208>; Scott FitzGibbon, *The Principles of Justice in Procreative Affiliations*, in *What's the Harm? Does Legalizing Same-Sex Marriage Really Harm Individuals, Families or Society?* pp. 125–54 (Lynn Wardle, ed., 2008).

35 *Halpern v. Canada (Attorney General)*, 225 D.L.R. (4th) 529 (2003).



Knowing who our close biological relatives are and relating to them is central to how we form our human identities, relate to others and the world, and find meaning in life.

Children—and their descendants—who don't know their genetic origins cannot sense themselves as embedded in a web of people, past, present, and future, through whom they can trace the thread of life's passage down the generations to them. As far as we know, humans are the only animals who experience genetic relationships as integral to their sense of themselves. We are learning now that eliminating that experience is harmful to children, biological parents, families, and society. We can only imagine how much more damage might be done to a child born not from the union of a man's natural sperm and a woman's natural ovum, but from 'gametes' constructed through biotechnology.

To summarize, at the very least, children's human rights with respect to their biological origins are:

1. for the child's origins to be natural and untampered-with;
2. for the child to know the identity of the progenitors of those origins; and
3. unless the contrary is unavoidable in the 'best interests' of a particular child, for the child to be in contact with those progenitors within a family structure—that is, to be reared by their biological mother and father within their genetic family.

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## Opinion Locked-in Happiness

Zac Alstin

A recent study by a Belgian doctor has revealed that a significant proportion of people suffering from Locked-in syndrome are happy.<sup>1</sup> These results are surprising, given that people with Locked-in syndrome suffer complete paralysis and are able to communicate either by blinking or through vertical eye movements. Yet of those who responded to the survey, only 28% considered themselves unhappy. The study has limitations due to the possibility that those who declined to take part in the study may be among the least happy. But it is startling to learn that any significant proportion of those living with Locked-in syndrome consider themselves happy.

Perhaps it should not surprise us. We all know that it is possible and even quite common for otherwise healthy people to suffer depression and despair. If a man in full possession of his own body can nevertheless endure abject misery, then

surely a man suffering from near-total physical paralysis can nonetheless enjoy normal happiness to some degree?

Disability advocates have long reported that the greatest challenges in their lives stem not from disability itself, but from the prejudice of others. This prejudice is most on display when we – as a community – unthinkingly reckon that the lives of the most severely disabled are 'obviously' not worth living. From our vantage point of relative health, we consider ourselves compassionate for extending to the severely disabled the 'option' of euthanasia. Likewise, the majority of the population will wince in apparent sympathy at the thought of a severely disabled child, and condone selective abortion as the 'merciful' end to a tragic existence.

How would we rather live: depressed but healthy, or happy but disabled? Obviously, in an ideal world we would all be happy and healthy. But the reality is that many people find themselves depressed, or disabled, or both. We can even

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<sup>1</sup> <http://bmjopen.bmj.com/content/early/2011/02/16/bmjopen-2010-000039.full>

consider depression a form of disability in its own right, since it has at last gained the attention it deserves as a serious illness.

So the real question is: can we be happy despite severe disability? The answer to this question has been proved in the affirmative. Can you imagine yourself being happy in a locked-in state? Of course not. The thought of being unable to move all but one's own eyelids is painful and frightening. Yet now we know that after a year, many people in such a state consider themselves happy. So although we are right to fear the deprivation of health, our fears should not be unlimited. We may be reassured by the resilience of human happiness in the face of such adversities.

The sad reality is that most of us will not stop to think about the possibility of genuine happiness in the face of disability in ourselves or in others. What is foremost in the minds of parents when 91-93% of unborn children receiving a positive test result for Down syndrome in the UK are aborted?<sup>2</sup> It is hard to imagine that future happiness is calmly and coolly considered, or that human adaptability is invoked to bolster confidence. Rather, I suspect that most people finding themselves in such circumstances would be afflicted with an unlimited range of fears about the future. As a 2006 study showed, the majority of women faced with information of an increased risk of Down syndrome suffered "strong reactions of anxiety and worries about the future" to such an extent that their coping mechanisms included trying "to live as if they were not pregnant any longer."<sup>3</sup> If my wife and I ever find ourselves in similar circumstances, I can only hope that someone nearby has the strength and confidence to say 'you will recover', that disability is not, of course, the end of the world nor even the end of human happiness.

If asked: would you rather be paralysed or depressed? I think most people would choose depression. This is in part due to our difficulty in imagining real depression, as well as our failure to understand the real significance of this

choice. I would not choose paralysis because I can imagine being unable to move my arms, and the very thought of it is depressing. Yet the thought of choosing depression instead is immediately uplifting: at least I will retain the use of my body, and that is a cheerful thought. We understand that true paralysis is sadly permanent, yet the emotional realm remains as mysterious and fluid as the sea. The optimist in us reckons that the body will not regain movement, but depression may lighten and lift. We are like children choosing between a hypothetical death-penalty or life imprisonment. Death is final, but life in prison means opportunity for escape or appeal, or early release.

When we consider these hypothetical dilemmas, we do not give much weight to the emotional state of depression. We don't take the dilemma seriously, because we have our own understanding of what makes us happy. We are attached to various standards and expectations of what constitutes a good life. That is why, even knowing that it is possible to live a happy life with locked-in syndrome, some people will still consider it an unworthy existence. That is also why some people will choose to abort their disabled children, not through fear of future struggle, but through simple rejection of it. I know I will adjust; I know I will be happy in time. But, I don't want to be happy under these conditions.

As the Locked-in syndrome study argued:

"The 'happy' subgroup of LIS survivors may indeed be those capable of high flexibility and plasticity who have fully succeeded in recalibrating, reprioritising and reorienting their needs and values, whereas the low raters cope poorly because they cannot shed the needs and values from their previous life."

The solution, therefore, is not simply to reassure people that everything will be alright, because happiness is so adaptable. Rather, everything will be alright because there are more important things than physical health, things that can be nurtured, imparted, and enjoyed despite the most severe disabilities. The most important of these abides in the respect with which we hold the very existence of others regardless of their condition. Disability is foremost a challenge to our values, not our happiness.

<sup>2</sup> Mansfield, C. et al. *Termination rates after prenatal diagnosis of Down syndrome, spina bifida, anencephaly, and Turner and Klinefelter syndromes: a systematic literature review. Prenatal Diagnosis. 19:9. September 1999. Pp808-812*

<sup>3</sup> Georgsson Öhman, S. et al. *Pregnant Women's Responses to Information About an Increased Risk of Carrying a Baby with Down Syndrome. Birth. 33:1. March 2006. Pp 64-73*

## Opinion

# Stem Cells and Utility: Shifting the Balance

Dr Gregory K Pike

It is hard to find a scientific field as misunderstood as stem cell research. Perhaps climate change or some branches of genetics – but that’s another story. Stem cell research is not only scientifically complex in its own right, but more importantly it interfaces with matters of profound importance to human life, matters that in themselves involve considerable misunderstandings – or at least lack of understanding. The volatile mix swirling around stem cell research includes hope of cures for diseases that cause great suffering, the significance of embryonic human life, cloning and human uniqueness, the intimate mixing of human and animal genetic material, novelties of all sorts in human reproduction, and ultimately the possibility of human enhancement.

Misunderstanding about stem cells happens at many levels. The most basic seems to be confusion about the different sorts of stem cells, their origins and capacities. The differences are critical to ethical deliberations. And at times the media has not been particularly helpful. But another and perhaps more worrisome misunderstanding comes from the fading public scrutiny that follows passage of legislation. Once the laws have passed it seems we think we can all relax in the knowledge that everything is in safe legal and regulatory hands. But it ain’t necessarily so. The real possibilities permitted by the laws sometimes only really begin to emerge with the passage of time. Apathy sets in and as the years go by incremental changes by way of case law and various minor amendments that fly under the radar of public scrutiny change the landscape.

Sometimes the public can then be surprised if they chance upon information about what actually happens. They had developed one view and yet reality turns out to be another.

Take for example another issue of moral significance. There is a mismatch between abortion practice and public perception and opinion. It is not uncommon to find people shocked to hear that about 96 percent of abortions in South Australia involve healthy babies and healthy mothers. They had thought that abortion was mainly about rape, incest, foetal abnormality and saving mothers’ lives. That was what they thought they had assented to. They can also express shock at the numbers of late term abortions of fully formed healthy foetuses. Their opinion about the morality of abortion is revealing. While there is strong support for abortion on the grounds of foetal disability, when it comes to a healthy

foetus and no abnormal risk to the mother, only 15% think abortion is morally justified.<sup>1</sup> Yet the majority of abortions are of this type.

But what about stem cell research? The public perception that stem cell research is morally justified seems to be founded upon the promise of imminent cures for terrible diseases at the cost of small numbers of embryos, each just a clump of cells, smaller than a full stop. And in any case many of them die naturally after conception, or will do so in an IVF programme. I recall attending a public parliamentary hearing in 2000 at which it was argued that not only were cures for Parkinson’s, Alzheimer’s, spinal cord injury, and diabetes now just a few years away, and artificial organs were on the near horizon, but moreover that just a few dozen embryos were really all that was needed to provide stem cell lines sufficient to supply researchers worldwide for the foreseeable future. This was from leaders in the field and yet on both counts it now sounds completely discordant with respect to what has transpired since.

The point is, there is a mismatch between public perception and reality. This is not a merely academic question for several reasons. First, because trust is fragile. The community, thinking highly of the medical/scientific enterprise, trusts scientists to be open and honest with them as advances are sought. If trust is broken or damaged, there may be consequences. A key player, the UK’s Lord Winston, recognised as much.

The potential benefits of embryonic stem cell research have probably been oversold to the public, fertility expert Lord Winston says. He fears a backlash if science fails to deliver on some of the “hype” around the cells - as he believes may happen. He says the notion that a host of cures for serious, degenerative disorders are just around the corner is fanciful.<sup>2</sup>

Second, some of what is actually happening is contrary to the public will. Of course, it wouldn’t be the first time that has happened. But in this case, for example, the simple fact that the majority of licenses granted for the use of human embryos in Australia have nothing to do with stem cells, suggests a result contrary to what the public agreed to. It could even be construed that we were misled. The majority of licenses

1 J Fleming and S Ewing, *Give Women Choice: Australia Speaks on Abortion*, Southern Cross Bioethics Institute, April 2005.

2 J Amos, *Winston warns of stem cell ‘hype’*, BBC News, see <http://news.bbc.co.uk/1/hi/sci/tech/4213566.stm>

are for training IVF practitioners, developing new embryo culture media for IVF, and refining preimplantation genetic diagnostic tests to weed out genetically defective embryos.

A new review process is now underway<sup>3</sup>. The review committee will look at what has happened in the science so far, how the regulatory structure is working, what licenses currently exist in Australia and what they have achieved, what science might be held back, what the community standards are, and a range of other matters. They will likely report sometime around the middle of the year, but it is unlikely that there will be much media attention. And yet this is an important opportunity to take stock. Especially since the debate around the turn of the millennium revealed a public (and politicians) deeply divided, and there is nothing to indicate that has changed.<sup>4</sup>

It is important to revisit for a moment why the community saw fit in 2002 to change their mind about embryos in research and permit a regulated paradigm allowing embryo destruction. In a nutshell, the most prevalent view seemed to be that even though human embryos deserved respect<sup>5</sup>, their use was justified given the huge benefit that would soon come. Good alternatives were portrayed as lacking. In particular, there was nothing that could achieve what tailor made stem cells from cloned embryos could do. For many, it was a utilitarian calculus. A cost benefits analysis. And the cost was acceptable because the benefit was so great and there was no other choice. For a moment let's set aside the principled position that argues for the protection of human embryos regardless of possible benefit arising from their use. That has always been my view.

3 See <https://legislationreview.nhmrc.gov.au/2010-legislation-review>

4 In 2006, the Prohibition of Human Cloning for Reproduction Act passed the Senate by just one vote. Moreover, two well-conducted pieces of research into attitudes to therapeutic cloning reveal that the majority of Australians are opposed to it. The first by Swinburne University of Technology in 2004 found that 63% were opposed (<http://www.swinburne.edu.au/lss/acets/monitor/2004MonitorFULL.pdf#search=%22Swinburne%20cloning%22>), and the second by Southern Cross Bioethics Institute in 2005 found that 55% were opposed [John I Fleming, *Analysis of new data on Australian attitudes to abortion, pregnancy counselling and alternative ways to reduce the frequency of abortion in Australia*. In: *Common Ground*, Eds John I Fleming and Nick Tonti-Filippini, St Pauls, Strathfield, NSW, 2007]. A Morgan Poll dealing with the same issue found the opposite, but the wording of questions was misleading and so it cannot be considered accurate.

5 What type of respect permits embryo destruction is an interesting question in its own right.

The argument based upon cost versus benefit now faces a new reality. The ethical concerns about respecting embryos or creating cloned ones have not changed. What has changed is that cures have not come. In fact not a real lot has.

Stem cell researchers have created an illusion of progress by claiming regular advances in the 12 years since human embryonic stem cells were first developed. But a notable fraction of these claims have turned out to be wrong or fraudulent, and many others have amounted to yet another new way of getting to square one by finding better methods of deriving human embryonic stem cells.<sup>6</sup>

What else has changed? Adult stem cell advances have steadily continued and there are many therapeutic applications. But most dramatically, the development of induced pluripotent stem (iPS) cells has opened the way for disease-specific stem cells for research and tailor made stem cells for treatment. Exactly what cloned ES cells were supposed to achieve but have so far failed to deliver.

The point is this. A contentious issue that was endorsed on balance should now, on balance, be opposed.

However, what is likely is that some scientists will instead argue that there should be more freedom, not less. What will be sought is permission to increase egg supply for cloning experiments by paying women for their eggs and a license to create human animal hybrids for research. Both cloning and hybrids are scientifically highly dubious, let alone ethically odious. Neither should be allowed. Scientists will serve society far better if they leave both well alone.

Which raises the question, why the apparent bloody-mindedness to press for more in the face of poor results and good alternatives? Could it be that despite rhetoric about respect for embryos, in fact proponents regard embryos as entirely valueless? Or is it that science should be free of constraint because of the privileged position it holds in some minds? Or perhaps the *theoretical* promise in the human embryo is just too enticing.

Whatever the case, those committed to some kind of cost benefit calculus have a big job ahead of them if they wish to argue in favour of the status quo. Those who press for more have an even bigger task.

6 Nicholas Wade, *Rare Hits and Heaps of Misses to Pay For*, *New York Times*, 8 Nov 2010, see [http://www.nytimes.com/2010/11/09/science/09wade.html?\\_r=1](http://www.nytimes.com/2010/11/09/science/09wade.html?_r=1)



# Report

## The Medically Supervised Injecting Centre – An Evidence Based Approach to Drug Policy?

By Matthew Tieu

### Introduction

In this report I begin by discussing the information presented in the major reports published on the efficacy and achievements of the Medically Supervised Injecting Centre (MSIC) in Kings Cross over the last decade of its operations. I summarise the main results of those reports and demonstrate that they do not provide any substantive evidence that the MSIC has achieved its objectives. Therefore, one can only conclude that the New South Wales government's recent legislation to enable the permanent operation of the MSIC is more likely to reflect an uncritical acceptance of a particular kind of harm reduction strategy rather than a critical evidence-based approach to drug policy. In the broader social context, the government is therefore faced with the difficulty of having to reconcile this particular harm reduction strategy with the greater goal of minimising or eradicating the social and economic burden of drug related crime and disease.

The initial debate responsible for the establishment of the MSIC occurred during the NSW Drug Summit in 1999, in which it was proposed that there be a trial of an injecting room carried out in a supervised environment. Legislation was subsequently passed in 2000 to establish the MSIC on a trial basis for 18 months initially<sup>1</sup>.

The objectives of the trial were:

1. Decrease drug overdose deaths
2. Provide a gateway to drug treatment and counselling
3. Reduce problems associated with public injecting and discarded needles and/or syringes
4. Reduce the spread of disease such as HIV, Hepatitis B and Hepatitis C

At the end of this initial trial period an independent evaluation of the MSIC's efficacy was published in a 2003 report<sup>2</sup>. Due to the inconclusive results of this report the NSW government subsequently endorsed and legislated for two further trial extension periods. The first of these saw the trial period extended to 2007<sup>3</sup> during which a number of "interim evaluation" reports on the efficacy of the MSIC were published<sup>4 5 6 7 8</sup>. A second extension was subsequently granted until 2011<sup>9</sup> however a year prior to the proposed trial deadline an evaluation report on the efficacy of the MSIC was published by KPMG<sup>10</sup>, and subsequently on October 27<sup>th</sup> of 2010 the Parliament of New South Wales passed a Bill entitled "Drug Misuse and Trafficking Amendment (Medically Supervised Injecting Centre) Bill 2010". This new

2 *Final Report of the Evaluation of the Sydney Medically Supervised Injecting Centre (2003)*. MSIC Evaluation Committee. [http://www.druginfo.nsw.gov.au/\\_\\_data/page/1229/NDARC\\_final\\_evaluation\\_report4.pdf](http://www.druginfo.nsw.gov.au/__data/page/1229/NDARC_final_evaluation_report4.pdf)

3 *Drug Summit Legislative Response Amendment (Trial Period Extension) Bill 2003*

4 *Interim Evaluation Report No 1: Operation and Service Delivery (November 2002 to December 2004), May 2005*. [http://www.nchecr.unsw.edu.au/NCHECRweb.nsf/resources/Interim\\_eval\\_Rep1/\\$file/INT\\_EVAL\\_REP\\_+1\\_SYD\\_+MSIC.pdf](http://www.nchecr.unsw.edu.au/NCHECRweb.nsf/resources/Interim_eval_Rep1/$file/INT_EVAL_REP_+1_SYD_+MSIC.pdf)

5 *Interim Evaluation Report No 2: Evaluation of Community Attitudes towards the Sydney MSIC, March 2006*. [http://www.nchecr.unsw.edu.au/NCHECRweb.nsf/resources/Interim\\_eval\\_Rep1/\\$file/INT\\_EVAL\\_REP\\_+1\\_SYD\\_+MSIC.pdf](http://www.nchecr.unsw.edu.au/NCHECRweb.nsf/resources/Interim_eval_Rep1/$file/INT_EVAL_REP_+1_SYD_+MSIC.pdf)

6 *Interim Evaluation Report No 3: Evaluation of Client Referral and Health Issues, March 2007*. [http://www.nchecr.unsw.edu.au/NCHECRweb.nsf/resources/Interim\\_eval\\_rep\\_2/\\$file/IntEvalReport3SMSIC+.pdf](http://www.nchecr.unsw.edu.au/NCHECRweb.nsf/resources/Interim_eval_rep_2/$file/IntEvalReport3SMSIC+.pdf)

7 *Interim Evaluation Report No 4: Evaluation of service operation and overdose-related events, June 2007*. [http://www.nchecr.unsw.edu.au/NCHECRweb.nsf/resources/Interim\\_eval\\_rep\\_2/\\$file/EvalRep4SMSIC.pdf](http://www.nchecr.unsw.edu.au/NCHECRweb.nsf/resources/Interim_eval_rep_2/$file/EvalRep4SMSIC.pdf)

8 *Economic Evaluation of the Medically Supervised Injection Centre at Kings Cross (MSIC) August 2008 Final Report*. [http://www.druginfo.nsw.gov.au/\\_\\_data/page/1189/MSIC\\_Final\\_Report\\_26-9-08.pdf](http://www.druginfo.nsw.gov.au/__data/page/1189/MSIC_Final_Report_26-9-08.pdf)

9 *Drug Summit Legislative Response Amendment (Trial Period Extension) Bill 2007*

10 *Further evaluation of the Medically Supervised Injecting Centre during its extended Trial Period (2007-2011)*. Final report – KPMG. [http://www.health.nsw.gov.au/resources/mhdao/msic\\_kpmg\\_pdf.asp](http://www.health.nsw.gov.au/resources/mhdao/msic_kpmg_pdf.asp)

1 *Drug Summit Legislative Response Act 1999*

legislation essentially allows the MSIC, which had previously operated as a trial that began on 1st May 2001, to operate on a permanent ongoing basis<sup>11</sup>.

### 1. Decreasing Drug Overdose Deaths?

One of the claims made in the initial 2003 report was that opioid overdoses may have been fatal had they occurred elsewhere and not under the supervision of the MSIC. It was estimated that at least approximately 4 to 9 deaths per year were prevented due to the interventions of staff at the MSIC (pg. 59). However, in this report it was stated that with regard to opioid overdoses:

In the months preceding the opening of the MSIC, the number of opioid overdose ambulance attendances and deaths decreased dramatically in the Kings Cross vicinity and across NSW. These decreases were attributed to a substantial reduction in the supply of heroin in Australia that occurred at the same time (pg. 44).

And with regard to heroin overdose deaths:

There was no evidence that the operation of the MSIC affected the number of heroin overdose deaths in the Kings Cross vicinity (pg. 44)

Furthermore, with regard to ambulance and emergency attendances:

Subsequent to the opening of the MSIC, there were further reductions in the number of opioid overdose ambulance attendances in the Kings Cross vicinity and across NSW. These reductions were associated with ongoing decreased heroin availability. It was not possible to distinguish the role of the MSIC in reducing demand on ambulance services from the effect of the continued reduction in heroin availability (pg. 44).

In an interim report during the second phase of the trial<sup>12</sup>, it was again acknowledged that the heroin shortage was a confounding factor however, this was supposedly addressed by including an experimental control (a comparison with the rest

of NSW) in the analyses of opioid-related deaths and ambulance attendances at suspected opioid overdoses. It was found that while there were no statistically significant differences in the rates of decrease in opioid related deaths between Kings Cross and the rest of NSW, there was a decrease in ambulance attendances at suspected opioid overdoses in the Kings Cross vicinity during the operating hours of the Sydney MSIC compared with the rest of NSW (Pg. 31). This claim is also supported by the most recent evaluation published in 2010 by KPMG<sup>13</sup>.

However, a confounding factor that has not been considered or mentioned in any of the reports is the increased policing with the aid of sniffer dogs in the Kings Cross area which began in May 2002<sup>14</sup>. The role of this kind of law enforcement may have had a significant impact on ambulance callouts. This was highlighted in an independent evaluation published by Drug Free Australia (DFA). They claim that when introduced in Cabramatta, "sniffer dogs, along with associated policing measures, reduced ambulance callouts by 83%"<sup>15</sup>.

Interestingly the 2010 KPMG report does not draw any conclusions about the impact that the MSIC has had on preventing opioid related deaths. It states:

The absolute numbers of opioid-related deaths in the Kings Cross area are too low to draw out trends around deaths. In addition the absence of opioid-related death data for the period prior to the commencement of the MSIC means it is not possible to comment on the impact the MSIC has had on opioid-related deaths. (Pg. 185).

Clearly the reports from all three trial phases provide very little evidence to suggest that the MSIC is responsible for reducing overdose related deaths in Kings Cross and surrounding postcodes.

11 *Drug Misuse and Trafficking Amendment (Medically Supervised Injecting Centre) Bill 2010*

12 *Interim Evaluation Report No 4: Evaluation of service operation and overdose-related events, June 2007.* [http://www.nchechr.unsw.edu.au/NCHECRweb.nsf/resources/Interim\\_eval\\_rep\\_2/\\$file/EvalRep4SMSIC.pdf](http://www.nchechr.unsw.edu.au/NCHECRweb.nsf/resources/Interim_eval_rep_2/$file/EvalRep4SMSIC.pdf)

13 *Further evaluation of the Medically Supervised Injecting Centre during its extended Trial Period (2007-2011). Final report – KPMG.* [http://www.health.nsw.gov.au/resources/mhdao/msic\\_kpmg\\_pdf.asp](http://www.health.nsw.gov.au/resources/mhdao/msic_kpmg_pdf.asp). Pg. 178-182.

14 <http://www.abc.net.au/news/s559063.htm>

15 [http://www.drugfree.org.au/fileadmin/Media/Global/2010\\_Update\\_Injecting\\_Room.pdf](http://www.drugfree.org.au/fileadmin/Media/Global/2010_Update_Injecting_Room.pdf)

## 2. Provide Gateway to Treatment?

The 2003 report concludes that MSIC clients were more likely to report that they had started treatment for their drug use than non-MSIC drug users (pg. 98-103). At the end of the first trial phase a total of 1,385 referrals (751 verbal and 634 written) for further assistance had been made for 577 MSIC clients (15%). During this phase a study of the rate of referral uptake revealed that of the 634 written referrals, 129 referral cards were returned. This data suggests that the rate of referral uptake as a proportion of total registered clients of the MSIC (3,810) was relatively low. It is stated in the 2003 report that "one in 20 MSIC clients received a written drug treatment referral... and 1% of MSIC clients were confirmed attenders at the referred drug treatment agency" (pg. 99). Again, this is very low proportion of referrals made and confirmations of referral uptake.

However, this is likely to be an underestimate of the actual number of referrals/referral uptake due to limitations with the referral card methodology (e.g. clients misplacing their referral card, agencies not requiring them or not returning the referral cards to the MSIC). Furthermore, it is worth bearing in mind that the study only accounts for approximately half of referrals since the other half were verbal referrals.

Another result discussed in the 2003 report was that referrals appeared to be targeted more towards those who were frequent attendees of the MSIC (42% who visited on more than 10 occasions received a referral). This explains why clients who visited the MSIC with greater frequency were more likely to have confirmed referral uptake. Similarly, the 2010 KPMG report also demonstrates that those with a greater frequency of attendance (constituting 2-7% of the MSIC clients) were more likely to accept a referral.

64% of frequent attenders (>98 total visits) accepted a referral to drug treatment, whereas only 1% of infrequent attenders (1-2 total visits) accepted a referral to drug treatment. Similarly, 60% of frequent attenders (>98 total visits) accepted a non-drug treatment referral, compared to 1% of infrequent attenders (1-2 total visits). (Pg. 136).

First one should bear in mind that not all referrals are specifically for drug addiction treatment which, as shown in the 2003 report, constituted only 43% (601 total) of the referrals, with 32%

(439 total) being health care referrals and 25% (345 total) social welfare referrals (pg. 98-99). Very similar percentages were observed for the period 2001-2004 as stated in the interim report, with the total number of referrals offered also similar at 16% (Pg. 25). The 2010 KPMG report presents cumulative data on these proportions from the commencement of the MSIC until 2010. Thus at 2010 there were a total of 8,508 referrals made, with 3,871 drug treatment referrals (45%), 2,278 health care referrals (27%), and 2,359 social welfare referrals (28%).

Second, only 15% of clients received any kind of referral at all (as stated in the 2003 report) which is a relatively low number of referrals made at all. Similar figures were also observed in the interim report which states that 16% of MSIC clients received a referral (pg. 25). Furthermore, the total rates of referral decreased and remained fairly low from 2006 onwards as stated in the 2010 KPMG report. There were 860 referrals for the year 2006-2007, 801 (2007-2008), 779 (2008-2009) and 648 (2009-2010) (pg. 124).

Therefore, on the basis of the relatively low and declining referral rates, the efficacy of the MSIC serving as a gateway to treatment is still relatively low. Perhaps this also demonstrates a lack of demand on the part of MSIC clients for referral services offered by the MSIC, particularly for drug addiction treatment. This is reinforced by the data in the 2010 KPMG report that only 1% of infrequent attendees (which constitutes over 90% of the total MSIC clients) accept referrals to drug treatment or non-drug treatment services. This demonstrates that referrals for the treatment of drug addiction are not a priority of the MSIC nor are they a priority of the majority of those who visit the MSIC.

## 3. Public Amenity?

In the first trial phase, telephone surveys targeted towards residents and Kings Cross business owners were conducted before and after the opening of the MSIC to gauge perceptions of different forms of public annoyance due to illicit drug use (e.g. negative image, crime and safety, discarded syringes, attracting drug users, harassment or begging and drug dealing). These results were initially published in the 2003 report, though a further telephone survey was conducted during the second phase of the trial in 2005, which was

then published in an interim report<sup>16</sup>. This survey was repeated in the third phase of the trial in 2010 and published in the 2010 KPMG report.

Both the 2003 and 2005 reports indicate that the main types of public annoyance most frequently reported by local residents were publicly discarded syringes, negative image to the area, crime and personal safety, tragedy of drug use, harassment or begging and public injecting (pg. 113 and pg. 14 respectively). The 2003 report states that whilst the residential respondents were consistent in what they regarded as major forms of public annoyance, there were some significant changes in the way business owners responded. Whilst negative image, crime and safety, and public injecting annoyances remained the same between 2000 and 2002, there were large increases in the citing of other public annoyances. For example, almost twice as many respondents reported crime and safety to be a public annoyance, three times as many cited the attracting of drug users to the area to be an annoyance, almost six times as many reported drug dealing to be an annoyance and almost twice as many cited the ineffectiveness of control as an annoyance (pg. 112-114).

Of the local residents surveyed in the first trial phase, 84% (in 2000) and 86% (in 2002) reported having seen syringes discarded in public places. Similar proportions of business respondents also reported having seen syringes discarded in public places, 90% (in 2000) and 87% (in 2002) (pg. 115). The 2005 report indicates that there was a slight decline in the reports of residential respondents (78%) and business respondents (82%) (pg. 12-13). There were further declines reported in the 2010 KPMG report with residential respondents (76%) and business respondents (80%) (pg. 174).

Higher levels of publicly discarded syringes are also an indication of public injecting therefore syringe counts conducted can also serve as a measure of public injecting. Independent syringe counts were performed by the Kirketon Road Centre (KCR) Clean-up Team, The National Centre in HIV Epidemiology and Clinical Research (NCHECR), and the South Sydney Council during 2000 to 2002. As discussed in the 2003 report, they all reported that there was a rapid short term increase in the number of publicly discarded

syringes after the MSIC opened. However, there was an overall decrease in the average number of syringes collected per month after the opening of the MSIC compared with the previous year, though there was subsequent trend of gradual increase (pg. 117-120). There were no significant changes in the number of syringes that were distributed in Kings Cross (pg. 121-123).

The data on syringe counts published in a 2007 interim report<sup>17</sup> indicate that the overall trend of lower numbers of publicly discarded syringes observed after the MSIC opened continued through to 2007, an overall reduction of 48% (pg. 33). The 2010 KPMG report states that when comparing the needle counts 2003 to 2004 and 2008 to 2009, there has been an overall reduction of 55% (pg. 168).

Whilst there was a significant decrease in publicly discarded syringes after the opening of the MSIC and marginal decreases in local residents and business owners who reported fewer sightings of episodes of public injection and discarded needles, a major caveat to this study was the fact that there was a heroin shortage (as mentioned previously) that began in the months prior to the opening of the MSIC. This is acknowledged in the 2003 report (as well as the interim reports).

Syringe counts in Kings Cross by the Needle Clean-Up Team, researchers and the Council, were generally lower after the MSIC opened than before, although increased levels were recorded at some sites, and there was a subsequent trend of gradual increase detected"... it was not possible to determine whether the decrease in discarded syringes was due to the prolonged reduction in the availability of heroin that commenced several months before the MSIC opened rather than any reduction in public injection due to the MSIC. (Pg. 124).

After the first trial phase of the MSIC, the conclusion regarding the effect that the MSIC had on public nuisance associated with discarded syringes and public injecting, as stated in the 2003 report, is as follows:

Even though the number of syringes discarded on the streets of Kings Cross subsequent to

<sup>16</sup> *Interim Evaluation Report No 2: Evaluation of Community Attitudes towards the Sydney MSIC, March 2006.* [http://www.nchechr.unsw.edu.au/NCHECRweb.nsf/resources/Interim\\_eval\\_Rep1/\\$file/INT\\_EVAL\\_REP\\_+1\\_SYD\\_+MSIC.pdf](http://www.nchechr.unsw.edu.au/NCHECRweb.nsf/resources/Interim_eval_Rep1/$file/INT_EVAL_REP_+1_SYD_+MSIC.pdf)

<sup>17</sup> *Interim Evaluation Report No 4: Evaluation of service operation and overdose-related events, June 2007.* [http://www.nchechr.unsw.edu.au/NCHECRweb.nsf/resources/Interim\\_eval\\_rep\\_2/\\$file/EvalRep4SMSIC.pdf](http://www.nchechr.unsw.edu.au/NCHECRweb.nsf/resources/Interim_eval_rep_2/$file/EvalRep4SMSIC.pdf)



the establishment of the MSIC decreased marginally, it is difficult to discount the contribution of the reduced availability of heroin. It was also not possible to determine whether fewer syringes on the street reflected a reduction in episodes of injection in public places. Certainly local residents reported sighting significantly less episodes of public injection as well as less syringes discarded in public places. (Pg. 125).

As far as the role which the MSIC may have played in helping reduce the numbers of publicly discarded syringes, the KPMG report is reluctant to draw any conclusions.

It is important to bear in mind that the data provided below are entirely from the period following the opening of the MSIC. In the absence of needle collection data for the period prior to the opening of the MSIC, it is not possible in this analysis to comment directly on the impact of the MSIC on needle collection following its opening. (Pg. 168).

Another confounding factor to bear in mind is the tougher police enforcement (with the aid of sniffer dogs) in Kings Cross that began in May 2002 (12 months after the injecting room opened), which may have pushed drug users and dealers further away<sup>18</sup>. Furthermore, nursing staff of the MSIC were also interviewed to gauge their opinions on the report and one in particular stated that any reduction in the level of publicly discarded syringes or public injection "could also be due to the police sniffer dog campaigns which has pushed people to darker corners further away" (pg. 30).

#### 4. Reduce The Spread of Disease?

The number of newly diagnosed incidences of HIV (Human Immuno-Deficiency Virus), HBV (Hepatitis B Virus) and HCV (Hepatitis C Virus) infections in the vicinity of the MSIC (Kings Cross, Darlinghurst and Surry Hills) was investigated and compared with the number of cases reported from the rest of Sydney and NSW. The results are presented and discussed in the 2003 and 2010 KPMG report. (The interim reports do not provide any specific data or discussion on this objective).

<sup>18</sup> <http://www.abc.net.au/news/newsitems/200205/s559063.htm>

The 2003 report indicated that there was a steady trend of increased notification of HIV infections from the Kings Cross postcode, increasing 15% per year from 1998-2002 (pg. 69). However, it is stated that the most common mode of transmission of HIV is due to homosexual activity amongst men rather than injecting drug use (pg. 79). The 2010 KPMG report indicates that after 2002 there was a modest downward trend in notifications of HIV infections for the Kings Cross postcode, compared with a slight upward trend for the rest of NSW (pg. 36).

Notifications of HBV infections remained stable from 1998-2002 in the surveyed areas whilst there was an increase in the rest of Sydney (pg. 71-72). The 2010 KPMG report does not present any specific data on HBV infections.

The 2003 report indicates that notifications of newly diagnosed HCV infection remained stable in the Kings Cross postcode, but increased in the surrounding Darlinghurst/Surry Hills postcodes and the rest of Sydney. Interestingly, the 2003 report states that there was a trend of increased HCV prevalence among injectors surveyed in Kings Cross as well as those who reported use of the MSIC. However, the report speculates that:

It is likely that the high prevalence of HCV among this group reflects the client base and target population of the MSIC, that is older people who have been injecting for longer periods of time and those with high levels of dependence and injecting risk behaviours. (Pg. 80).

The 2010 KPMG also reports a higher prevalence of HCV among new MSIC clients. However it is suggested that this could also be due to the greater potential for transmission of the Hepatitis C virus, that it is able to remain viable outside the body for a longer period than HIV or Hepatitis B (pg. 81). Whilst the 2003 report concedes that there was an increased prevalence of HCV (as discussed above), it concludes that there is no discernable increase in HIV or HBV infections among injecting drug users (pg. 80).

The 2010 KPMG report presents data over a longer period of time and claims that from 1999-2009 there was an overall downward trend in the notifications of HCV in both the Kings Cross postcode and throughout NSW. However, the downward trend in the Kings Cross postcode only represents a 21% decrease as opposed to

the 41% decrease measured for the rest of NSW (pg. 36-37). However, the 2010 KPMG report is reluctant to draw any conclusions with regard to this objective stating that:

The rates of Hepatitis C, HIV and Hepatitis B infection recorded for MSIC clients is consistent with the rates found in previous studies. However, it is difficult to assess the impact that the MSIC has had, if any, on the rates of infection of these viruses. (Pg. 81)

The MSIC's provision of injecting and vein care advice aims to reduce the risk of transmitting blood borne diseases that arise due to poor injecting technique and syringe sharing. Reports from all three trial phases indicate that MSIC clients generally practice safer injecting behaviour and are less likely to inject in public places which places them at greater risk of contracting diseases. Combined with the small proportion of drug treatment and health care referrals that clients receive, this data suggests that the MSIC is providing a contribution towards decreasing the spread of blood borne diseases transmitted through promoting and educating drug users on safer injecting practices. However, given that the reports provide no evidence of any significant decreases in the incidence of HIV, HBV and HCV in the Kings Cross postcode, there is no evidential basis upon which to claim that this objective has been achieved.

### **Summary**

The reports from all three phases of the trial concluded that the operation of the MSIC in the Kings cross area was feasible and that the MSIC should continue its operations. However, it is clear that this is not justified because of the lack of any evidential basis upon which the MSIC can claim to have achieved any of its four main objectives to any substantive degree.

The results of the reports clearly acknowledge that firstly, the reduction in opioid overdoses could not be attributed to the operations of the MSIC due to the co-occurrence of a nation-wide shortage of heroin supply. Despite this acknowledgment, the 2003 report makes the speculative claim that "the MSIC probably did reduce opioid overdoses amongst those who used the facility", estimating that 4 deaths per annum were averted (pg.203). Yet the KPMG report is reluctant to draw any conclusions about the role the MSIC may have played stating that "the absence of opioid-related

death data for the period prior to the commencement of the MSIC means it is not possible to comment on the impact the MSIC has had on opioid-related deaths" (pg. 185).

Secondly, whilst the report does conclude that the MSIC provides a "gateway" to drug treatment for a small proportion of MSIC clients, this is a very modest outcome. The 2003 report itself states that the rates of referral from the MSIC "fall within the lower bounds of the range reported for IDU (injecting drug users) seeking drug treatment referrals in needle and syringe programs and community health settings" (pg. 203-204). It is likely that the majority of the clients of the MSIC are not interested in seeking any kind of drug addiction treatment referrals at all.

Thirdly, due to the heroin shortage, the observed reductions in discarded needles and syringes and public injecting cannot be solely attributed to the operations of the MSIC, despite the claims made in the reports that the MSIC played a role in improving public amenity. The 2010 KPMG report could only speculate that "it is reasonable to assume that at least a proportion of the 604,022 injections conducted at MSIC in the last 10 years would otherwise have occurred in public places" (pg. 31). Increased police law enforcement within Kings Cross is likely to have pushed drug users away and thus may have contributed to decrease in discarded needles and syringes as well as preventing an escalation in drug related crime. One cannot therefore discount the potential of the MSIC to attract drug related crime.

Fourthly, the 2003 report concludes that there was no evidence of an increase or decrease in notifications of HIV, HCV or HBV in the Kings Cross area attributable to the MSIC. However, there was an increase in HCV prevalence among injectors Kings Cross as well as those who reported use of the MSIC. The 2010 KPMG report suggests that the MSIC may not have had any impact on the prevalence of those diseases at all.

### **Conclusion**

Whilst the results of the studies presented at the end of the first trial phase (in the 2003 report) clearly demonstrate that there was no evidence that the MSIC had achieved its objectives, one could have been warranted in claiming that further studies were required. This was indeed the basis upon which the NSW government decided in 2003 to legislate for an extension of the trial

period until 31<sup>st</sup> of October 2007, thus constituting a second trial phase<sup>19</sup>. In a speech made by Ms. Reba Meagher (Cabramatta—Minister for Health) on the 5<sup>th</sup> of September 2003, she discusses the impetus for the Bill which would grant an extension on the trial period of the MSIC<sup>20</sup> (emphasis added).

All aspects of the current licence, the terms and conditions for operating the centre and the trial remain unchanged for the additional period. However, in line with this Government's evidence-based approach to drug policy, the trial over the next four years will continue to be carefully monitored...The extension will also provide an opportunity for information and data to be collected over a longer period and to take account of any changes in the drug market, such as any changes in the supply of heroin.

At the end of this second trial phase there was still very little evidence presented in the interim reports to establish whether the MSIC had achieved its objectives. The status of the efficacy of the MSIC in 2007 was essentially no different to 2003. In a subsequent speech to parliament<sup>21</sup> made by Ms. Reba Meagher on June 7<sup>th</sup> 2007 she states:

A further trial period will also enable a longer term evidence base to be established as to the effectiveness of the centre. This is of particular importance, given the long-term drug use of its client group and will inform any future decisions on permanency of the centre.

This would be the third and final trial period of the MSIC, though as it turns out the trial phase would be attenuated a year before its conclusion by the introduction of new legislation to allow the MSIC to operate on a permanent ongoing basis.

When introducing the Bill to parliament<sup>22</sup>, Ms. Carmel Tebbutt (Marrickville—Deputy Premier and Minister for Health) stated that:

The Government has made the decision to continue the Medically Supervised Injecting Centre as an ongoing program following strong evidence from numerous independent evaluations that the centre is achieving those objectives.

As discussed in this report, it is clear that there is no evidential basis upon which the MSIC can claim to have achieved its four objectives. Therefore this decision does not reflect an evidence-based approach to drug policy but rather it is likely to have come from an agenda aimed at promoting and implementing a harm reduction strategy regardless of the results of the trials.

The official policy concept underpinning national and state public health strategies is "Harm Minimisation" (as discussed in the National Drug Strategy 2004–2009 and the 2010–2015 draft)<sup>23 24</sup>. The core aims are to reduce supply and demand for drugs as well as reduce the levels of harm associated with drug use. These "harm reduction" strategies constitute one element of the harm minimisation concept. They are designed to prevent or limit specific harms arising from the use of drugs. The aim of a harm reduction strategy is to avoid exacerbating harm caused by misuse of drugs without necessarily condoning or endorsing drug use. However, a significant conflict emerges from this equivocation. Many advocates of the harm minimisation concept tend to accept that people choose to use drugs, and therefore they are not interested in whether drug users have made a prudent choice. Their focus is solely on reducing harm due to the risks associated with drug use. Therefore, it follows that the only recourse that they believe is available to drug users is to ensure that harms are not made worse

19 Drug Summit Legislative Response Amendment (Trial Period Extension) Bill 2003

20 Extract from NSW Legislative Assembly Hansard and Papers - NSW Hansard Articles : LA : 05/09/2003 : #6 [http://www.parliament.nsw.gov.au/prod/parlment/nswbills.nsf/7bd7da67ee5a02c5ca256e67000c8755/3158d0c4666ff079ca256d9500366221/\\$FILE/A4703.pdf](http://www.parliament.nsw.gov.au/prod/parlment/nswbills.nsf/7bd7da67ee5a02c5ca256e67000c8755/3158d0c4666ff079ca256d9500366221/$FILE/A4703.pdf)

21 Extract from NSW Legislative Assembly Hansard and Papers Thursday 7 June 2007. [http://www.parliament.nsw.gov.au/prod/parlment/nswbills.nsf/0/3b87d96596ec7beaca2572f3002d5e0c/\\$FILE/LA%201707.pdf](http://www.parliament.nsw.gov.au/prod/parlment/nswbills.nsf/0/3b87d96596ec7beaca2572f3002d5e0c/$FILE/LA%201707.pdf)

22 Extract from NSW Legislative Assembly Hansard and Papers Wednesday 22 September 2010. [http://www.parliament.nsw.gov.au/prod/parlment/nswbills.nsf/0/51e975631477f96fca2577a6001a6823/\\$FILE/LA%208110.pdf](http://www.parliament.nsw.gov.au/prod/parlment/nswbills.nsf/0/51e975631477f96fca2577a6001a6823/$FILE/LA%208110.pdf)

23 The National Drug Strategy: Australia's integrated framework 2004–2009. <http://www.nationaldrugstrategy.gov.au/internet/drugstrategy/Publishing.nsf/content/framework0409>

24 The National Drug Strategy 2010–2015: A framework for action on alcohol, tobacco, illegal and other drugs. Consultation Draft December 2010. <http://www.nationaldrugstrategy.gov.au/internet/drugstrategy/publishing.nsf/Content/consult-draft>

for them by providing them with safer equipment to use (e.g. clean syringes) and safer environments to inject (e.g. the MSIC). In contrast to harm reduction, an alternative perspective that is based on a broader and more internally consistent harm minimisation concept is one that is defined in terms of non drug use as the primary goal rather than harm reduction. This is simply because abstinence gives rise to the lowest possible level of harm associated with drug use, as well as the lowest possible level of supply and demand.

Whilst it may have been expected that the MSIC would contribute to reducing overdose related harms and prevent transmission of blood borne diseases, there is no substantive evidence to demonstrate that the MSIC has achieved any of these harm reduction goals in its 10 years of operation thus far. The operation of the MSIC during its decade long trial phase is still regarded as an experimental approach to harm reduction as stated in the recent draft of the National Drug Strategy 2010-2015, but it will be interesting to see what the final version has to say about the outcome of this experiment.

In relation to injecting drug use, needle and syringe programs have been the main harm reduction approach, helping to slow the spread of blood-borne viruses like HIV and hepatitis C. Readily available needle disposal facilities and other strategies as simple as well-lit streets have helped to improve community amenity in areas where injecting drug use takes place. Some jurisdictions have experimented with other approaches,

including a medically supervised injecting centre in one jurisdiction. (Pg. 25)

Clearly, the decision to have the MSIC operate on a permanent ongoing basis is more likely to reflect the government's harm reduction agenda. Though, one wonders whether it also demonstrates that the community (particularly the local residents and business owners and injecting drug users of Kings Cross) is content to have this drug issue swept under the rug rather than properly dealt with.

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