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The welfare of the child principle and the use of PGD: selecting for disability

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Introduction

Campbell and Cabrera argue in this volume ‘that prospective parents should be free to take such steps as they think fit to have what they regard as healthy and capable children’, adding the caveat ‘provided this does not cause undeniable harm, to these children or to other people, which is sufficiently serious to outweigh the presumptive case for reproductive freedom’.¹ Notions of parental freedom and harms to children will be explored in a more specific context in this chapter: that of preventing the use of embryos for treatment based on their genetic make-up.

The enactment of the Human Fertilisation and Embryology Act 2008 (HFEA 2008) may be viewed as enhancing the scope for choice of those who wish to become parents through assisted reproduction in the UK, largely due to its provisions concerning the possibility of founding families outside the two parent heterosexual model and its minor revision of the welfare principle.² The approach taken by the HFEA 2008 was to a considerable extent based on the House of Commons Select Committee on Science and Technology (HCSTC) report: *Human Reproductive Technologies and the Law*.³ This report had been criticised by some members of the Committee for having taken an ‘extreme libertarian approach’, their dissenting views being reflected in a special report issued at the same time as the substantive report.⁴ However, in one area the HFEA 2008 has taken a uniquely restrictive step. For the first time in the UK, legislation has sought to make it impermissible, at least in certain circumstances, to choose to try to have children

¹ See Chapter 2.

² Part 2 of the HFEA 2008, and s. 14(2), amending s. 13(5) of the HFEA 1990.

³ Fifth Report of Session 2004–5, *Human Reproductive Technologies and the Law*, vol. 1, HC 7–1, London: Stationery Office, 24 March 2005.

⁴ HC 491, 24 March 2005.

that are known to have particular genetic constitutions. Testing of gamete donors may enable these kinds of decisions to be made before embryos are created and restrictions are imposed on preferential selection of donors where there is a significant risk of genetic abnormalities being passed on to children.⁵ However, the principal technique under consideration here will be prenatal genetic diagnosis (PGD), involving genetic testing of embryos.⁶ The idea that a state would involve itself through legal regulation in decisions about the genetic make-up of children and intrude on the reproductive choices of potential parents in this way raises troubling questions, despite the apparently beneficent motive of preventing children being born with potentially devastating genetic conditions. While concerns about the appropriate weight to be given to the welfare of children born through assisted reproductive technology were clearly prominent during the reviews of existing legislation and practice that led to the passage of the HFEA 2008, there was also a perceived need for clarity concerning when techniques such as PGD should be deemed to be acceptable and legally permissible.⁷ It will be argued here that if achieving clarity was a principal aim of the new legislative provisions, they may in fact fall short of achieving this goal. It will be suggested that they may provide some scope for interpretation that would allow potential parents who wished to do so to attempt to select embryos for disability, despite the legislative intent to the contrary. Even so, the retention of the general welfare principle in the amended HFEA 1990 may still render such attempts null and void, highlighting the need to consider the appropriateness of a child welfare test in this context. It also raises the issue of whether the new provisions serve any practical purpose, if the end result could have been achieved through use of the welfare principle. It will be concluded that their real effect is most likely to be in the message they may be perceived to send about the undesirability of having children with genetic disorders.

⁵ Section 13(9) of the HFEA 1990, as amended.

⁶ The history of the development of PGD and the current methods of performing it are discussed elsewhere in this volume.

⁷ See for example, HCSTC, Fifth Report of Session 2004–5, *Human Reproductive Technologies and the Law*.

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The HFEA 2008 amends in many significant ways the original statute regulating particular methods of medically assisting reproduction: The Human Fertilisation and Embryology Act 1990 (HFEA 1990). Hereafter they will be referred to collectively as the HFE Acts,⁸ save when reference to a specific Act is necessary. The HFE Acts prohibit certain activities absolutely.⁹ Other specified activities can only be carried out with a licence issued by the Authority. The type of licence relevant to this discussion concerns activities in the course of providing treatment services.¹⁰ Performing such activities without a licence is a criminal offence carrying penalties of imprisonment up to ten years or a fine or both.¹¹

Schedule 2 of the amended HFEA 1990, specifies the kinds of activities that may be authorised under licence. Those critical to PGD are the following:

- (a) bringing about the creation of embryos *in vitro*,
- (b) procuring, keeping, testing or processing or distributing embryos,
- ...
- (d) other practices designed to secure that embryos are in a suitable condition to be placed in a woman,
- (e) placing any permitted embryo in a woman

The procedures undertaken in PGD are hence covered here: from the initial creation of *in vitro* embryos, to testing them and finally transferring them to a woman as part of treatment.

Section 14 of the HFEA 2008 modifies the conditions of licences for treatment contained in s. 13 of the HFEA 1990 to include the following:

⁸ For a comparison of the HFE Acts, see Birk, D. *Human Fertilisation and Embryology: The New Law*, Bristol: Jordan, 2009.

⁹ Section 41 HFEA 1990, as amended, lists offences and penalties.

¹⁰ Section 11(1)(a) and Schedule 2 HFEA 1990, as amended.

¹¹ Sections 4 and 41(2) HFEA 1990, as amended

- (9) Persons or embryos that are known to have a gene, chromosome or mitochondrion abnormality involving a significant risk that a person with the abnormality will have or develop—
- (a) a serious physical or mental disability,
 - (b) a serious illness, or
 - (c) any other serious medical condition,
- must not be preferred to those that are not known to have such an abnormality.

Similar restrictions are placed where testing involves gender-related genetic disorders.¹² These will not be discussed separately.

On an initial reading, these provisions may seem to allow for no discretion in the use of embryos found to have an abnormality or to carry a risk of illness or disability, once a condition has passed the requirement of sufficient seriousness, and this threshold must be passed to allow PGD to take place at all.¹³

In addition to these provisions, it is also important to note the general ‘child welfare’ principle which forms part of licence conditions. This must be considered in all treatment decisions governed by the HFE Acts:

13(5) HFEA 1990, as amended

A woman shall not be provided with treatment services unless account has been taken of the welfare of any child who may be born as a result of the treatment (including the need of that child for supportive parenting), and of any other child who may be affected by the birth.

¹² Sections 13 (10) and (11), HFEA 1990 as amended.

¹³ Schedule 2 1ZA (2).

A failure to comply with the requirements of s.13 is not itself a criminal offence,¹⁴ unlike certain other practices prohibited by the HFE Acts, such as placing an embryo in a woman other than a permitted embryo.¹⁵ Nevertheless, although a breach of the standard licensing conditions in itself would not lead to prosecution, it could result in the HFEA taking proceedings to suspend or revoke a clinic's licence, so they are very likely to be observed.¹⁶ Effectively, the licensing conditions act as a legislative restriction on the choices of couples seeking treatment services governed by the HFE Acts by limiting the freedom of providers to offer such services. The HFEA's regulatory role has been reinforced by the introduction of a specific statutory duty upon it to promote compliance with the requirements of the HFE 1990 and with the Code of Practice it issues under section 25 of the HFE Acts.¹⁷ Its duties also now include maintaining a statement of the general principles which it considers should be followed in carrying out its activities under the Act and its functions in relation to such activities.¹⁸ It has been suggested that 'the Authority has always defined its general role by reference to its statutory remit. This new requirement is likely to produce a more detailed breakdown of its role in respect of particular and specific activities and functions.'¹⁹

In order to examine the potential impact of the new s. 13 restrictions on treatment following embryo testing, it is useful to consider examples of how they might be applied. For the sake of simplicity, it will be assumed that both gamete providers are intending to parent any child born as a result of the assisted reproduction service.

The application of the new embryo-testing provisions

¹⁴ Section 25(6) HFEA 1990, as amended.

¹⁵ Section 3(2) HFEA 1990, as amended.

¹⁶ Sections 18, 19 and 25 HFEA 1990, as amended.

¹⁷ Section 8(1)(9cb) HFEA 1990, as amended.

¹⁸ Section 8(1)(ca) HFEA 1990, as amended.

¹⁹ Birk, *Human Fertilisation and Embryology*, para. 4.19.

PGD results in a possible choice within a batch of embryos – couple does not wish to use an affected embryo

In this example, the couple has a number of embryos in storage and is seeking to avoid a specific disorder which comes within the terms of being a condition that can be tested for using PGD. All of the embryos are tested, and the results show that only one of these embryos is affected. The couple chooses to avoid using the affected embryo.

This is the most likely scenario to arise in practice. The vast majority of people who seek to use PGD will do so precisely to avoid particular genetic disorders due to a family history of a condition or increased risk of disorders, such as those associated with conception of children by older gamete providers. Should such a condition be detected in a particular embryo following PGD, their conclusion will almost inevitably be to reject this embryo for implantation in favour of one that does not have this condition. In such situations, there is no need to bring into play any of the new section 13 restrictions, as the potential parents' preference is in line with them.

However, matters may not be entirely simple even here. Schedule 2 of the HFEA 1990 as amended contains further provisions concerning activities which may be licensed, and added in embryo testing as one of these activities.²⁰ Embryo testing can only be carried out for one or more specified purposes. These include establishing parenthood and tissue-typing where a sibling suffers from a serious medical condition to enable selection of an embryo that could be a match for potential donation to the sibling. The purposes that are relevant here, though, are the provisions relating to testing for genetic abnormality.²¹

Schedule 2 S1ZA

(1)

²⁰ As amended by Schedule 2 of the HFEA 2008.

²¹ Sex-related disorders are dealt with in Schedule 2 S1ZA (1)(c), HFEA 1990, as amended.

- (a) establishing whether the embryo has a gene, chromosome or mitochondrion abnormality that may affect its capacity to result in a live birth,

- (b) in a case where there is a particular risk that the embryo may have any gene, chromosome or mitochondrion abnormality, establishing whether it has that abnormality or any other gene, chromosome or mitochondrion abnormality.

In addition, Schedule 2 IZA (2) provides that a licence cannot be issued for embryo testing unless the Authority is satisfied ‘that there is a significant risk that a person with the abnormality will have or develop a serious physical or mental disability, a serious illness or any other serious medical condition’. Difficulties in the interpretation and application of condition-based criteria are discussed by Jackson in this volume.²²

Nevertheless, once a condition has been authorised by the HFEA as one that can be tested for, it would seem to follow that a decision can be legitimately taken to choose not to implant any tested embryo. Of course it is the case that a woman could not be forced to accept the implantation of any embryo due to the extreme violation of respect for her autonomy and bodily integrity that this would entail, and either gamete provider could withdraw consent to the use of embryos created with their gametes before treatment was provided.²³ However, the point is that the couple could *prefer* to use unaffected embryos to those that are known to have a genetic condition disclosed by PGD. That choice is consistent with the approach taken by the new s. 13 provisions which seek to avoid such embryos being used for treatment.

²² See Chapter 4.

²³ Schedule 3, para. 4 of the HFEA 1990, as amended. Although withdrawal of consent is now subject to a 12-month ‘cooling-off’ period, the effective right of veto of the use of embryos by a gamete provider is maintained.

It is also possible that if one condition is tested for, but the embryo is found to have other abnormalities, the couple could decide not to use it. Once the criteria for permitting PGD to take place have been satisfied, the detection of any other disorder meeting the criteria of sufficient seriousness would seem to permit it to be discarded in preference to other embryos. This would also be consistent with s. 13, which refers to ‘embryos that are known to have a gene, chromosome or mitochondrion abnormality’, rather than being restricted to considering them only in respect of the condition that was originally being tested for. Section 13 prohibits their use in preference to embryos not known to have such an abnormality. The implications of this will be explored later, but it must follow that to discard such embryos in favour of others that are not known to be affected is a choice that lawfully can be made by a couple.

PGD results in a possible choice within a batch of embryos all of which are tested – couple wishes to use an embryo that may be affected by a genetic disorder

Of course, the obvious question might be why a couple would wish to use an affected embryo when they have others that could be used instead? Though it might be supposed that most potential parents would seek to avoid passing on genetic disorders, there are occasional examples of people seeking to make such reproductive choices. The scenario that has caused most discussion is where a couple deliberately seeks to have a child with a genetic condition for social reasons. The classic example is congenital deafness, illustrated by a deaf lesbian couple in the United States of America, although they did not actually use PGD. Ms Duchesneau and Ms McCullough sought to increase the chance of having a child who would be deaf by using a deaf friend as a sperm donor. Their decision has provoked considerable academic debate on the merits or otherwise of ‘choosing for disability’.²⁴ The couple contended that deafness is a culture, not a disability and that

²⁴ Mundy, L., ‘A world of their own’, *Washington Post* 31 March 2002, W22; Sprigg, M., ‘Lesbian couple create a child who is deaf like them’, *Journal of Medical Ethics* 28 (2002): 283; Levy, N., ‘Deafness, culture and choice’, *Journal of Medical Ethics* 28 (2002): 284–5; Anstey, K.W. (2002) ‘Are attempts to have impaired children justifiable?’, *Journal of Medical Ethics* 28 (2002): 286–8; Savulescu, J.,

rather than deafness reducing the child's capacity, being able to hear would constitute a lack of capability in their child since a hearing child would be prevented from full participation in deaf culture.²⁵ Using PGD to select an affected embryo could make the difference between increasing the chances of having a deaf child to making this a certainty. Another example can be found in the condition of achondroplasia. Its most obvious feature is that it is the commonest cause of disproportionately short stature, or dwarfism, although it may be associated with other medical complications.²⁶ Achondroplasia is an FGFR3 gene mutation which shows autosomal dominance in inheritance. Where both partners carry the mutation, in natural conception there is a 25 per cent chance of an unaffected pregnancy, a 50 per cent chance of an affected pregnancy, and a 25 per cent chance of a pregnancy where the child carries two copies of the mutation, which is usually fatal shortly after birth. It has been suggested that a couple with achondroplasia might seek not only to avoid the possibility of conceiving a child with the lethal combination of genes but to have a child with achondroplasia, rather than one without.²⁷ Again the reasons for this would be parental preference for a child like themselves, or practical issues in caring for the child.²⁸

'Deaf lesbians, "designer disability" and the future of medicine', *British Medical Journal* 325 (2002): 771–3.

²⁵ Darshak, M., Sanghavi, M.D., 'Wanting babies like themselves, some parents choose genetic defects', *New York Times* 5 December 2006.

²⁶ Horton, W.A., Hall, J.G., Hecht, J.T., 'Achondroplasia', *Lancet* 370(9582) (2007): 162–9; Stratbucker, W.B., Serwint, J.R., 'In brief: achondroplasia', *Pediatrics in Review* 30 (2009): 114–15.

²⁷ Kolthoff, M., 'Assisted reproduction and *primum non nocere*', *Virtual Mentor* 9(9) (2007): 605–10.

²⁸ The HCSTC used the example of achondroplasia in its on-line consultation launched 22 January 2004. In it, a fictional couple gave as the reason for wishing to use PGD to select for achondroplasia that a child of normal height would cause practical problems in their home.

Although the circumstances in which there might be a deliberate attempt to use PGD to conceive a child with a particular genetic disorder are likely to be rare in practice, there is evidence that they have been made. Baruch *et al.* surveyed American clinics offering PGD and found that 3 per cent of respondents reported having intentionally used PGD ‘to select an embryo for the presence of a disability’.²⁹ It is exactly this kind of choice that s. 13 of the amended HFEA 1990 is directed against. Indeed this is made crystal clear in the explanatory note that accompanied a draft of the Human Tissues and Embryos Bill published in 2007. Following a description of the intention to make it a condition of treatment licences that embryos tested and known to have specified abnormalities were not to be preferred in treatment services to those which did not, and that this prohibition would also extend to the selection of persons as gamete or embryo donors, it went on to say:

There have been reported cases outside the UK involving the positive selection of deaf donors in order deliberately to result in a deaf child. The new section [as numbered] would prevent this.³⁰

It follows that, in this scenario, a deliberate choice to select an affected embryo in preference to others that were unaffected would be prevented. This may pose particular problems for couples with conditions such as achondroplasia, where one possibility is that an embryo will have a combination of genes incompatible with survival. Although amniocentesis or chorionic villus sampling can be performed during pregnancy to detect double dominant mutations, the use of PGD would enable decisions to be made without having to consider abortion where this variation is found to exist. However, there may be

²⁹ Baruch, S., Kaufman, D.J., Hudson, K.L., ‘Genetic testing of embryos: practices and perspectives of US IVF clinics’, *Fertility and Sterility* 89 (2008): 1053–8; Baruch, S., Kaufman, D.J., Hudson, K.L., ‘Preimplantation genetic screening: a survey of in vitro fertilization clinics’, *Genetics in Medicine* 10 (2008): 685–90.

³⁰ Department of Health, Human Tissue and Embryos (Draft) Bill, May 2007, Cm 7087, para. 66.

couples with achondroplasia who, while they might not prefer to have a child who also has a single copy of the mutation and who is affected by the condition, would be content with this. The same of course may be true for other genetic conditions, but unless they have variants which are likely to be fatal or cause additional problems for the child, couples who have no preference would be unlikely to opt for PGD.³¹ If a woman had undergone screening during pregnancy, there would be no question of forcing her to undergo a termination of pregnancy, whether the foetus had a single or even double copy of the mutated gene. However, if PGD were undertaken to avoid the fatal mutation, then could a decision be made to use an embryo with the single mutation? According to the new provisions, it would appear not, at least if they had other embryos that were free from the mutation.³² While wishing to avoid a fatal condition, and the consequent decision that might arise as to whether to abort a pregnancy, it appears that women using PGD who might have chosen to carry an embryo with achondroplasia could be denied that opportunity under the new provisions.

However, it may be argued that the legislation was not intended to achieve this outcome and that there are means of interpretation that would avoid it. One possible solution might be to focus on the wording of the legislative provisions, which are couched in terms of 'preference'. It could be suggested that if a couple were willing to have either a child with achondroplasia or one without, that they are not in fact expressing a preference for a child with a genetic disorder. If this were accepted, then they could be permitted to use an embryo chosen at random from the embryos that do not have the fatal genetic combination, but which may include embryos with and without the

³¹ See for example a survey of children of deaf adults where more than 70 per cent stated no preference for a hearing or deaf child, and believed that genetic selection for and against deafness was not appropriate. Mand, C., *et al.* 'Genetic selection for deafness: the views of hearing children of deaf adults', *Journal of Medical Ethics* 35 (2009): 722–8.

³² The issue of the comparator group to which an affected embryo is being preferred will be considered in more detail later.

non-fatal mutation. This would appear to satisfy the intention of the provisions to prohibit deliberately using affected embryos for treatment but allow some room for manoeuvre for potential parental choice to run the risk of a child having what is likely to be regarded as a disabling medical condition. The potential parents in such a situation are not 'preferring' an embryo with such a condition, nor seeking to select one on this basis; merely they are accepting the possibility.

There are some grounds to suggest that the provisions might bear such an interpretation since, despite the clear intention behind them, it does not necessarily follow that even where there is a known risk that an embryo may have a genetic abnormality or be of a sex giving rise to the risk of a resulting child having a serious physical or mental disability, serious illness or serious medical condition, it cannot be implanted. This is apparent from the guidance given in the HFEA's 8th Code of Practice in relation to embryo testing.³³ There is no absolute prohibition on implanting such embryos. In addition, although the Code of Practice omits to refer to the preferential selection of embryos here, the wording of the statute does appear to make 'preference' a necessary criterion for the restrictions on embryo selection to apply. Furthermore, there is no requirement that couples submit their embryos to PGD. Rather, the expectation is the opposite: that PGD is currently seen as requiring justification in defined circumstances and is not to be used as routine practice. There is no statutory requirement that a couple with a known inheritable disorder, or where there is a clear risk of a genetic abnormality in an embryo, have to agree to PGD on embryos created with their gametes before they can use them in treatment. Similarly, donors who are known to have such disorders or be at risk for them are not prevented from providing gametes under s. 13(9); it is only preferentially selecting them that is prevented. In fact, it is possible that limitations on providing treatment to couples or using donor gametes might be placed where there is a known risk of embryos having genetic disorders, but these would need to rest on a different provision – that of the general welfare of a resulting child, contained in s. 13(5). This will be explored further in due course. For the moment, I will turn to an even more

³³ HFEA, 8th Code of Practice, London: Stationary Office, 2009, 10C.

contentious possibility – that the prohibitions on embryo selection may not prevent a deliberate attempt to select for an embryo with a genetic disorder.

PGD undertaken on one embryo at a time – couple wishes to use an affected embryo

Here the couple chooses not to undertake PGD on a batch of embryos, but rather only one embryo at a time is created and tested. For the sake of argument, the first embryo tested has a genetic disorder that is contained in the HFEA's authorised list of conditions for testing, but the couple wishes to use it for treatment.

My contention would be that the conditions set out in ss. 13(9)–(11) may not prevent them from making this choice. This is because of the wording of these provisions which is expressed in terms of 'preference' in selection, comparing the affected embryo with others that are 'not known' to have the abnormality or carry the risk.

This is reinforced by the guidance given in the HFEA's 8th Code of Practice on the interpretation of the restrictions on selecting embryos for treatment in s. 13 of the HFEA 1990, as amended:

The law prohibits the selection of an embryo for treatment if it is known to:

- (a) have a gene, chromosome or mitochondrial abnormality involving a significant risk that the person with the abnormality will develop a serious physical or mental disability, a serious illness, or a serious medical condition, or
- (b) be of a sex that carries a particular risk that any resulting child will have or develop a gender-related serious physical or mental disability, serious illness, or serious medical condition

This applies only where there is at least one other embryo suitable for transfer that is not known to have the characteristics. Where there is no other embryo

suitable for transfer, an embryo with these characteristics may be transferred. [at 10C, Emphasis added]

The issue then becomes what the comparator group for the affected embryo is. There are a number of possible options here. These could include all *in vitro* embryos; embryos donated for other people's treatment or embryos created using the couple's gametes. Another factor would relate to whether these other embryos would need to currently exist or whether the possibility that they could be created would be relevant. Presumably some territorial restriction would operate so that only *in vitro* embryos coming under the remit of the HFE Acts would be contemplated. Which comparator group the affected embryo is being 'preferred' to will determine whether or not these restrictions bite.

It should be said at the outset that there is a difference between embryos 'known not' to be affected, and those 'not known' to be affected. The former suggests that there has been a positive test to determine the genetic make-up of the embryo, the latter does not. So for example, if the requirement against preference was that embryos known to be affected could not be preferred to those known not to be affected, the scope for selecting affected embryos might be increased by simply not testing all of the embryos at the same time. There would then be no other embryos which were *known* not to have the condition and hence the prohibition on selection would not come into effect. While there might still be room for doubt here, since the comparator group of embryos would remain to be determined, requiring the comparator group to have been tested and found not to have the condition would make it more likely that the couple could avoid the restriction since there is no general requirement to conduct PGD.

However, this is not what the provisions say. They require a preference to be expressed in comparison with embryos that are not known to be affected. This still would seem to permit a wide or a narrow scope for such a comparison to be made. There are strong arguments against the idea of a very widely drawn category of comparator embryos. It may be contended that there should be a realistic possibility of the couple

being able to access and use an alternative embryo. For example, the fact that other people have embryos stored for their own treatment that are not known to be affected by genetic disorder would not allow the couple with the affected embryo to seek to use them. It would therefore be absurd to suggest that in seeking to use their own embryo, they are 'preferring' to do so than to use these other embryos. This is not a choice that is open to them. This supports immediately narrowing the category of comparator embryos to those that could be available to the couple to use, which leaves only embryos that are donated for other people's treatment and other embryos of the couple.

The next issue is whether the other embryos must actually be in existence at the time that the comparison is being made or whether the possibility of future unaffected embryos that they could use can be brought into consideration. The response to this is less obvious, since there is no guidance as to the timeframe in which the comparison need be made. Again however, it can plausibly be argued that the preference which the couple expresses should be directed to options that are currently available to them, not predicated on some, as yet uncertain, prospect of being able to secure donated embryos or successful creation of embryos from their own gametes that are not known to have disorders. This would suggest that the comparator group that the s. 13 provisions are concerned with are other embryos that the couple has available to use at the time when decisions about the affected embryo are being made. This seems to be implied from the HFEA guidance which refers to 'no other embryos being suitable for transfer', which suggests that the comparator embryos must be available for transfer at the time the decision is being made.³⁴

If this is accepted, and it is fair to say that this remains a speculative approach, then it would seem to follow that if the couple do not have any other embryos in existence, they would not fall foul of the ss. 13(9–11) treatment provisions by seeking to use the affected embryo. As noted earlier, these do not provide a blanket prohibition on the use of embryos that have been tested and found to have particular genetic conditions; only upon

³⁴ Ibid., at 10C.

preferring to use them to those that are not known to have such conditions if there 'is at least one other embryo suitable for transfer that is not known to have the characteristics'.³⁵ For a couple determined to seek to have a child with a particular genetic make-up, the route might accordingly be to ask to have embryos created and tested serially and consenting to the disposal of embryos found not to have the condition until one is found to have it. Consent could be withdrawn for an unaffected embryo's continued storage; it could be donated for treatment of others, training purposes or for research. Any of these options would render it unavailable for a couple's own treatment.³⁶ Embarking on this route would rest on the feasibility of having gametes available to use to create embryos in this way. It is likely to involve egg freezing which, as the HFEA notes, 'is still a relatively new and experimental technique' and has a low success rate in maintaining viable gametes.³⁷ Although additional methods such as vitrification are becoming available which appear to improve the chances of eggs surviving the freezing and thawing processes:

Records show that up to 31/12/2008, around 6388 eggs have been stored in the UK for the patient's own use. To date around 88 embryos from stored eggs have been created. These embryos were transferred to women in around 32 cycles, which resulted in around 3 live births. These figures are for both eggs which have been stored using slow freezing and vitrification methods.³⁸

This would also require the willingness of clinics to participate in what would clearly be an attempt to circumvent the statutory provisions. Nevertheless, such circumvention would not appear to be unlawful nor to directly contravene current HFEA policy. The

³⁵ Ibid.

³⁶ HFEA 1990 s. 12(1), s. 14(12), s. 15(4) and Schedule 3, as amended.

³⁷ HFEA website, 'Freezing and storing eggs', www.hfea.gov.uk/46.html (accessed on 11/11/2011.)

³⁸ Ibid.

HFEA's 8th Code of Practice, having allowed for the possibility that embryos known to have genetic abnormalities can be implanted, goes on to say:

10.17

The use of an embryo known to have an abnormality as described above [in 10C] should be subject to consideration of the welfare of any resulting child and should normally have approval from a clinical ethics committee.

10.18

If a centre decides that it is appropriate to provide treatment services to a woman using an embryo known to have an abnormality as described above, it should document the reason for the use of that embryo.

NOTE: An example of an embryo not suitable for transfer in this context is one that has no realistic prospect of resulting in a live birth.

Therefore, even if the specific statutory restrictions on selecting affected embryos can be avoided, it is entirely possible that such a practice would still be caught by the more general restrictions of the HFEA 1990, if the implantation of an affected embryo was thought to sufficiently risk any resulting child's welfare. There is, therefore, a two-stage process in considering whether embryos can be implanted where PGD is involved: first the embryo-testing provisions in ss. 13(9-11), and secondly the welfare provisions in s. 13(5).

It has been asserted that the underlying justification for limiting the use of embryos found to have genetic abnormalities is based on the welfare of the child principle. The basis for this assertion will be considered in more detail, before turning to two fundamental issues that deserve closer examination: to what extent is the concept of the welfare of the child really appropriate in this context, whether it is the reason behind those sections related solely to PGD or in the overarching conditions for treatment in s.

13(5); and how should it be balanced against respect for the wishes of the potential parents to select an embryo known to have genetic abnormalities?

The welfare of the child principle as a basis for embryo-testing provisions

The welfare of the child and the ss. 13(9–11) embryo-testing provisions

The development of the techniques of PGD was based on apparently beneficent grounds: to improve the success rates for assisted reproduction by not commencing a pregnancy with an embryo that has a serious disorder that might result in miscarriage; to avoid a choice having to be made whether to abort a foetus with a serious disorder identified during pregnancy and, underlying this, concerns about the welfare of children.³⁹ The development of the role of the HFEA in regulating PGD has been discussed elsewhere in this volume and so will not be repeated here. However, questions about the use of PGD to select for disability have been asked in a number of public consultations and reviews. For example, in 1999 a public consultation exercise was carried out by a joint working party of the HFEA and the Advisory Committee on Genetic Testing.⁴⁰ After outlining the potential choices that could be made to test embryos and act on the results, including seeking to use an affected embryo, it asked respondents ‘Can the principle of the Welfare of the Child ever be compatible with the decision to begin a pregnancy knowing that a child will be born with a genetic disorder?’ The responses were as follows:

³⁹ See for example, the *Report of the Committee of Inquiry into Human Fertilisation and Embryology* (Warnock Report), London: Stationary Office, 1984, para. 12.13.

⁴⁰ Human Fertilisation and Embryology Authority and Advisory Committee on Genetic Testing, *Consultation Document on Preimplantation Genetic Diagnosis*, London: Stationery Office, 1999.

47% acknowledged that there might be situations in which the replacement of an affected embryo would be compatible with the principle of the welfare of the child. 31% argued that this should be a decision left to the parents. 22% argued that starting such a pregnancy could never be compatible with this principle.⁴¹

Although the number of responses was small (98), and hence the weight that can be placed on them is limited, they revealed a range of factors that were thought to be relevant:

The majority of these responses qualified their answers by stating that this might only be appropriate in certain circumstances, depending on severity of the condition, family situation and other similar considerations. In addition, most of the ‘yes’ responses concerned only the question of affected embryos where there were no unaffected ones for transfer, but rejected PGD as a method of choosing an affected embryo for social or other reasons.

It should also be noted that many respondents were unfamiliar with the terminology of ‘welfare of the child’ and some respondents questioned its meaning, range or relevance.⁴²

It is interesting to see some doubts being expressed about the meaning of the welfare of the child principle and how it might apply in this situation.

On the specific issue of selecting for disability, the HCSTC in its report entitled *Human Reproductive Technologies and the Law* was ambivalent and did not reach a final conclusion on whether embryos with, as it termed them, ‘undesirable characteristics’ should be able to be used in treatment. On this issue it said:

⁴¹ Human Genetics Commission and the Human Fertilisation and Embryology Authority, *Outcome of the Public Consultation on Preimplantation Genetic Diagnosis*, London: Stationary Office, November 2001, paras. 30–3.

⁴² Ibid.

We can imagine that many clinicians would balk at the idea of selecting, for example, a deaf child using PGD, but we do not feel that the creation of a child with reduced life opportunities is sufficient grounds for regulatory intervention, else we might logically deny poor people IVF. Professor Tom Shakespeare told us that PGD should not be allowed to select out ‘minor or trivial’ conditions such as restricted growth or deafness. [Ev 363] On this basis, it is difficult to argue that they should not be selected rather than deselected. A more challenging but unlikely scenario would be the desire to select a child who would suffer obvious discomfort (rather than disadvantage), or worse. In this area there needs to be further debate.⁴³

It was therefore not at the behest of the HCSTC that the ss. 13 (9–11) provisions on embryo selection were included in the legislation, nor was any suggestion of this raised in the government response to this report.⁴⁴ However, a further consultation exercise undertaken by the Department of Health appears to have provided the basis for their inclusion in subsequent legislative proposals. This consultation specifically asked whether there should be a prohibition on deliberately screening in, or selecting for, impairments or disabilities as opposed to screening out, or selecting embryos free from impairments or disabilities.⁴⁵ Responses to the consultation were published in March 2006. There was no attempt in this document to draw conclusions, and it was noted that on the issue of screening in or selecting for impairments the responses demonstrated a

⁴³ Para. 145

⁴⁴ *Human Reproductive Technologies and the Law: Government Response to the Report of the HCSTC*, London: Stationary Office, Cm 6641, August 2005.

⁴⁵ Department of Health, *Review of the Human Fertilisation and Embryology Act: A Public Consultation*, London: London: Stationary Office, August 2005, para. 5.20.

range of perspectives.⁴⁶ Nevertheless, it appears likely that the impetus for including legislative provisions on this subject came from the HFEA's response, which sought parliamentary guidance. Following this consultation, proposals for legislation appeared in a White Paper issued in December 2006. Despite the lack of any clear consensus or recommendation for this approach in the prior consultative processes, it was stated that 'Deliberately screening-in a disease or disorder will be prohibited'.⁴⁷ While the sections in which this issue was addressed changed at different stages of the drafting of the Bill and its passage through Parliament, the fundamental principle of prohibiting a preference for affected embryos to those not known to be affected remained consistent.⁴⁸

As well as seeking to improve success rates in terms of live births in assisted reproduction, and to try to avoid the issue of abortion arising, as it might if abnormalities were discovered only during pregnancy, the inclusion of these provisions seems, therefore, to be rooted in some notion of the concept of child welfare.

The welfare of the child principle and child law

⁴⁶ Department of Health, *Report on the Review of the Human Fertilisation and Embryology Act: A Public Consultation*, London: Stationary Office, March 2006, para. 5.3.

⁴⁷ Department of Health, *Review of the Human Fertilisation and Embryology Act 1990: Proposals for revised legislation (including establishment of the Regulatory Authority for Tissues and Embryos)*, London: Stationary Office, December 2006, Cm 6989.

⁴⁸ See for example Draft Human Tissue and Embryology Bill published for pre-legislative scrutiny. May 2007, s. 21(4).

The need to take account of the welfare of children born as a result of treatment services governed by the HFE Acts may seem at first to be an uncontroversial proposition.⁴⁹ Concern to protect children is at the heart of international declarations such as the United Nations Convention on the Rights of the Child, which is the most widely ratified international convention in existence.⁵⁰ This Convention states in Article 3 that:

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

In the UK this approach may be seen to be reflected in the general legal principles that govern decisions about children. In England and Wales these are set out in the Children Act 1989, which provides that when hearing cases under the Act, the courts are required to have the welfare of the child as their paramount consideration. There are similar provisions under the equivalent statute in Scotland, the Children (Scotland) Act 1995. In England and Wales there is also the inherent jurisdiction which is usually exercised in wardship proceedings, although it may be used independently. Here, the principle is that judicial decisions must be made in the child's best interests.⁵¹ It can be argued that there are differences between the expressions set out in statute and at common law; however, largely for practical reasons, the courts have sought to minimise them so that the terms welfare and best interests are used interchangeably.

⁴⁹ I have explored the issues arising from the use of the welfare/best interests test in more detail in Elliston, S., *The Best Interests of the Child in Healthcare*, Abingdon: Routledge-Cavendish, 2007, esp ch 1. Some parts of this discussion are taken from it.

⁵⁰ The United Nations Convention on the Rights of the Child, adopted and opened for signature, ratification and accession by General Assembly Res. 44/25 of 20 November 1989. It came into force in the UK on 16 December 1991.

⁵¹ For the use of wardship, see for example *Re J (a minor) (medical treatment)* [1992] 3 WLR 507 CA; *R v. Portsmouth NHS Trust, ex part Glass* [1999] 2 FLR 905 CA.

However, equating the two terms is not unproblematic. It can be suggested that a welfare approach is less protective of children than a best interests approach, since, as has on occasion been recognised by the courts, if we are speaking of what is in a child's best interests, then logically there can be only one answer.⁵² This presents a number of difficulties – first in the actual prediction of what the outcome will be of a particular choice. Breen has suggested that this requires the decision-maker to have shaman-like qualities for the prediction of future events.⁵³ It also implicitly involves a value judgement: what factors are relevant to a person's interests and how are these factors to be weighed? Although it has been held that best interests encompass medical, emotional and all other welfare issues,⁵⁴ there may well remain ample scope for disagreement over what outcomes, to the extent they can be predicted, are best for a child. Evidence to support this can be found in the numerous treatment decisions brought before the courts in England and Wales, notably in the context of withholding or withdrawing treatment from severely ill children who have profoundly disabling conditions.⁵⁵

A welfare test by contrast can be suggested to be more flexible and less dogmatic, since it does not claim that there is one answer that is best, merely that a decision promotes or safeguards, or is at least not harmful to, the interests of the child. Of course,

⁵² *Re SL (adult patient) (medical treatment)* [2000] 2 FCR 452 CA, per Dame Elizabeth Butler-Sloss P., at p. 464.

⁵³ Breen, C., *The Standard of the Best Interests of the Child: A Western Tradition in International and Comparative Law, International Studies in Human Rights Vol.72*, The Hague: Martinus Nijhoff, 2002.

⁵⁴ *Re A (medical treatment: male sterilisation)* [2000] 1 FCR 193 CA, per Dame Butler-Sloss P., at p. 200.

⁵⁵ See for example *Re C (a minor) (withdrawal of lifesaving treatment)* (1997) 40 BMLR 31; *Re T (a minor) (wardship: medical treatment)* [1997] 1 WLR 242, [1997] 1 All ER 906, 35 BMLR 63 CA; *Wyatt v. Portsmouth Hospitals NHS Trust* [2005] EWCA Civ 1181 CA.

the problems of ascertaining and predicting the outcome of alternatives on child welfare will remain. A range of different outcomes for the child may be viewed as being in the child's interests, depending on the values and priorities given to particular aspects of child welfare and development. In fact, in the main, such decisions are devolved to parents to make, with relatively limited scope for intervention, unless it seems likely to result in what is regarded as serious harm. Indeed this can be considered to be part of a social contract:

It is a hallmark of a democratic society that while parents have the primary responsibility to look after their children, they are free to bring them up in the manner in which they deem best for the children's welfare.⁵⁶

Parents have the legal responsibility to safeguard and promote the child's health, development and welfare.⁵⁷ Nevertheless, the circumstances in which their decisions are open to challenge are relatively limited and it can be suggested that they generally hinge on a threshold of a significant risk of serious, avoidable harm being reached.

A further problem lies in deciding what weight the welfare of a child should be given. As we have seen, the United Nations Convention on the Rights of the Child states that 'the best interests of the child shall be a primary consideration' when decisions are taken by outside agencies, including courts.⁵⁸ This followed considerable debate over the wording to be used.⁵⁹ However, it is not the expression used in the Children Acts, which is that the child's welfare is the *paramount* consideration. At first glance, then, the Children Acts appear to apply a less protective standard of decision-making than the UN

⁵⁶ Thomson, J., *Family Law in Scotland*, 5th edn, Glasgow: Tottel, 2006, at p. 257.

⁵⁷ This is explicit in the Children (Scotland) Act 1995, s. 1(1)(a) and implicit in the Children Act 1989, s. 3.

⁵⁸ Article 3(1).

⁵⁹ Breen, C., *The Standard of the Best Interests of the Child: A Western Tradition in International and Comparative Law, International Studies in Human Rights Vol.72*, The Hague, Martinus Nijhoff, 2002, at pp. 78–84.

Convention, since they refer to child welfare rather than a child's best interests, but this factor is then given overriding importance, being *the paramount* consideration rather than *a primary* consideration. The test under the inherent jurisdiction of the courts in England and Wales is that the child's best interests are the prime and paramount concern.⁶⁰ However, as noted, the courts have sought to avoid imposing different standards when making decisions about children, whatever the procedure taken to bring a case before them. Effectively, therefore, the standard adopted is that the best interests of the child are the paramount concern of the court.

However, no legally enforceable rights attach to embryos as they are not regarded as legal persons, so decisions affecting them cannot be made on the basis of child welfare⁶¹ and it would effectively alter the provision of assisted reproductive treatment beyond recognition were this to be contemplated. Family law statutes such as the Children Act 1989 and the Children (Scotland) Act 1995 only apply to children after birth. Furthermore, the UK, upon its ratification of the United Nations Convention on the Rights of the Child, declared that it interpreted the Convention as applicable only following a live birth.⁶² Nevertheless, consideration of these instruments highlights the potential for disagreement over the standard of child protection that ought to apply in decisions concerning children, the weight that it should be given and the difficulties in

⁶⁰ See for example *Re J (a minor) (wardship: medical treatment)* [1990] 3 All ER 145, CA.

⁶¹ *Paton v. BPAS* [1979] 1 QB 276, considered by the EctHR in *Paton v. United Kingdom* (1981) 3 EHRR 408 (ECHR); *Kelly v. Kelly* 1997 SLT 896 CS (IH). The likely impact of a decision upon the welfare of a foetus or resulting child can only be considered indirectly in so far as it may affect the best interests of a pregnant woman who lacks capacity to make treatment decisions for herself: *St George's Healthcare NHS Trust v. S (No. 2)* [1998] 3 All ER 673 CA; *Re F (in utero)* [1988] FCR 529; [1988] Fam 122 (CA).

⁶² The UK Reservation and Declarations, CRC/C/2/Rev 4, at para. 32, 16 December 1991.

interpreting deceptively simple statements, even in the context of children who have legally recognised and protected interests. This also raises the issue of the legitimate role of the state in displacing the views of parents about what is in their children's interests and when their decisions can be regarded as so detrimental to child welfare that steps may be taken to protect children from them.

It should be said that some have questioned the continuing adherence to the central place of a principle of child welfare or best interests of the child in the era of human rights, and it has been contended that:

It will no longer do, it seems, to frame issues of child welfare in terms of making traditional 'best interests' judgments: at the very least, concern for a child's welfare should be conceptualised as a matter of the child's rights-protected interests.⁶³

While there is merit in this, welfare is the terminology used in domestic legislation and the content of such evaluations may be unlikely to differ in practice. For this reason, discussion in this chapter has concentrated on this concept.

The development and retention of the s. 13(5) welfare of the child principle within the HFE Acts

The difficulties in applying a welfare standard multiply when what is at stake is not parental decision-making concerning children they already have, but rather where the decision under consideration is whether to allow them to seek to have children using

⁶³ Brownsword, R., 'Happy families, consenting couples, and children with dignity: sex selection and saviour siblings', *Child and Family Law Quarterly* 17(4) (2005): 435–73, at 435.

assisted reproductive technologies. The restrictions on selection of embryos for treatment following PGD do not make any direct reference to the welfare concept, though as has been demonstrated, this is undoubtedly the justification for them; this is explicit in s13(5). The standard of child protection that is set out in this section is couched in the language of welfare rather than best interests. However, in respect of the weight to be given to it in deciding whether or not treatment services should be provided, this section does not prioritise the welfare of the child. It must be ‘taken into account’ but it is not the paramount, or even a primary, consideration on the face of the statute. This notwithstanding, it appears to be a provision that may assume considerable importance in determining whether specific embryos can be used in treatment services.

In the development of a legislative approach to reproductive technologies, concern to safeguard the interests of children who might be born as a result of assisted reproduction can be traced back at least to the Warnock Committee Report, and references are made to this issue in various contexts throughout it.⁶⁴ It is interesting to see, however, that, even then, there was disagreement about the extent to which such concerns should be a governing factor:

Our emphasis on the arguments may make it appear that there was a uniformity of approach and moral feeling in the Inquiry. The reality however has been that our personal feelings and reactions have been as diverse as those presented in the evidence. Some members have a clear perception of the family and its role within society; in considering the various techniques before us their focus has been on the primacy of the interests of the child, and on upholding family values. Other members have felt equally strongly about the rights of the individual within society.⁶⁵

⁶⁴ Warnock Report.

⁶⁵ *Ibid.*, para. 3.

In fact, when the White Paper introducing what came to be the HFEA 1990 was issued, it contained no specific reference to a child welfare principle, nor did the Bill itself. It came into consideration almost by chance in the course of debates about whether access to treatment should be confined to married couples and it was in this context that concerns about child welfare led to amendments to the Bill. Nevertheless, once the principle had been put forward, it commanded unstinting support. As Jackson, writing in 2002, notes:

In the Parliamentary debates leading up to the passage of the Human Fertilisation and Embryology Act in 1990, the inclusion of a welfare principle was neither challenged nor defended. Instead, it was simply assumed to be self-evidently true that their future children's welfare ought to be taken into account before a couple is offered assistance with conception, and this assumption undoubtedly persists today.⁶⁶

Indeed, it came to be considered that one of the 'most important principles' underlying the HFEA 1990 was the welfare of any children born.⁶⁷ However, a more critical appraisal of the welfare principle appeared in the Report of the HCSTC, where Recommendation 24 stated that:

The welfare of the child provision discriminates against the infertile and some sections of society, is impossible to implement and is of questionable practical value in protecting the interests of children born as a result of assisted reproduction... The welfare of the child provision has enabled the HFEA and clinics to make judgements that are more properly made by patients in consultation with their doctor. It should be abolished in its current form. The minimum threshold principle should apply but should specify that this

⁶⁶ Jackson, E., 'Conception and the irrelevance of the welfare principle', *Modern Law Review* 65 (2002): 176–203, at 177.

⁶⁷ *Evans v. Amicus Healthcare Ltd; Hadley v. Midland Fertility Services Ltd* [2004] 1 FLR 67 CA para. 37, *per* Wall, J.

threshold should be the risk of unpreventable and significant harm. Doctors should minimise the risks to any child conceived from treatment within the constraints of available knowledge but this should be encouraged through the promotion of good medical practice not legislation.⁶⁸

It is worth noting, however, that the HCSTC expressed most concern in respect of judgements being made about the prospective parenting environment. No issue was taken with the general idea of protecting children from harm, although the suggested threshold for any legislative provision was a relatively high one. While recommending that good medical practice should be sufficient to minimise risks of harm, this does, of course, raise the question of the proper extent of clinical discretion and whether it might be amenable to challenge, for example, through human rights principles.⁶⁹ Nevertheless, it might be expected that justification for the exercise of discretion in a particular case would be required.

However, in response to the HCSTC recommendations, the government only recognised ‘that attempting to frame these matters in national legislation and guidance which pays due regard both to individual circumstances and to the need for objectivity and fairness is extremely difficult’ and undertook to ‘seek wider public views on how the welfare of children born as a result of assisted reproduction may best be secured’.⁷⁰ This it did in 2005 in the Department of Health public consultation previously referred to.⁷¹ The questions asked included whether the welfare of the child principle should be retained and if so, whether this should be a matter of ‘good medical practice’ as

⁶⁸ Para. 107.

⁶⁹ Human Rights Act 1998. See for example, Bell, L., ‘Is the Human Fertilisation and Embryology Act 2008 compatible with the Universal Declaration of Human Rights (UDHR)?’, *Web JCLI* 1 [2009], available at <http://webjcli.ncl.ac.uk/2009/issue1/bell1.html> (accessed on 09/02/2012).

⁷⁰ *Human Reproductive Technologies and the Law*, paras. 39 and 40.

⁷¹ *Review of the Human Fertilisation and Embryology Act*, s. 3.

recommended by the HCSTC, or overseen by the HFEA. It also asked whether welfare should be restricted to consideration of the child's medical circumstances and whether it should be specified that risk assessment should relate to 'serious' or 'significant' harm. As with the questions asked about embryo testing, responses were mixed and no conclusions were drawn in the report on the consultation.⁷² In the end, the government rejected abolition of the welfare of the child provision, or even a major revision, opting instead to address only the assessment of future parental support for a resulting child. This principle therefore operates on two levels: as both a general condition for offering any assisted reproduction governed by the HFE Acts and now, in addition, as an implicit justification for the specific provisions concerning treatment involving PGD. As it stands, the provisions in the HFE Acts provide no guidance on how the welfare principle should be interpreted. This is provided instead by the HFEA in its Code of Practice.

The welfare principle and the HFEA Code of Practice

Concerns about the application of the welfare principle to treatment decisions resulted in the HFEA conducting its own review of this issue at the same time as the HCSTC was conducting its more wide-ranging review of the HFEA 1990 and the role of the HFEA.⁷³

As a result, the HFEA introduced a number of changes that it claimed would lead to a 'better system for protecting the welfare of children born as a result of fertility treatment'.⁷⁴ It went on to summarise some of the key changes as follows:

⁷² Department of Health, *Report on the Review of the Human Fertilisation and Embryology Act*, ch. 3.

⁷³ HFEA, *Tomorrow's Children: A consultation on guidance to licensed fertility clinics on taking in account the welfare of children to be born of assisted conception treatment*, London: Stationary Office, January 2005.

⁷⁴ HFEA press release 'Improved welfare checks system will be better, fairer and clearer for fertility patients, GPs and clinics', 2 November 2005.

A clear focus on areas of serious harm, with vague and subjective social questions removed from the assessment

That clinics should assume they will provide treatment unless there is evidence that the child is likely to be at risk of serious harm. This will enable treatment for the majority of patients to go ahead with the minimum of disruption.

Clinicians should use their professional judgement to decide which cases warrant further investigation rather than being obliged to contact a patient's GP in each and every case.⁷⁵

What is interesting to observe is the concentration on a risk-based assessment and, in particular, the emphasis on medical conditions that might affect a child resulting from treatment regulated by the HFEA.

The current guidance at the time of writing is the 8th Code of Practice which was produced to take account of the HFEA 2008. It includes the following provisions:

The centre should assess each patient and their partner (if they have one) before providing any treatment, and should use this assessment to decide whether there is a risk of significant harm or neglect to any child.⁷⁶

While some of the factors concern the criteria of 'supportive parenting', there is a specific consideration of the likely health of the child at 8.10:

(b)(iii) medical history, where the medical history indicates that any child who may be born is likely to suffer from a serious medical condition...

and more generally,

⁷⁵ Ibid.

⁷⁶ At 8.3.

(iv) circumstances that the centre considers likely to cause serious harm to any child mentioned above.

The Code of Practice states that the centre should refuse treatment if it:

- (a) concludes that any child who may be born or any existing child of the family is likely to be at risk of significant harm or neglect,
- or
- (b) cannot obtain enough information to conclude that there is no significant risk.⁷⁷

Despite offering such guidance, the statutory responsibility for making the assessment required by s. 13(5) remains that of the treatment centre, which must decide how to apply the welfare principle in an individual case. For procedures involving PGD, this would be the provision that would finally determine whether treatment could be provided if the hurdle of avoiding restrictions on using embryos at risk of or known to have genetic abnormalities can be overcome in any of the ways outlined earlier. However, where the question arises of using an embryo which has been tested and found to have abnormalities arises, the approval of a clinical ethics committee is also expected by the HFEA, adding another layer of scrutiny in this situation.⁷⁸

Applying the welfare principle to assisted reproduction

Notwithstanding the retention of the welfare principle, the importing of a familiar concept in child law to assisted reproduction has, as has already been indicated, provoked

⁷⁷ Ibid., para 8.15.

⁷⁸ HFEA, 8th Code of Practice, at 10.17.

a range of criticism.⁷⁹ Much of it stemmed from the application of this concept to the potential parenting environment that a child might be born into, especially related to the original version of s. 13(5) which required the ‘need of the child for a father’ to be taken into account. With the replacement of this wording with the ‘need for supportive parenting’ by the 2008 Act some of these concerns may have been addressed, although they do not disappear. However, there are more fundamental objections to the use of the principle at all when deciding whether reproductive treatment services should be offered.

The usual way of looking at a welfare of the child assessment is to attempt to weigh the relative burdens and benefits that would accrue to a child depending on the decision that is taken. A ‘balance sheet’ approach has been advocated in cases involving medical treatment, for example, where the provision of treatment to severely ill or disabled young children is under consideration.⁸⁰ While this is a far from straightforward approach even in these circumstances, it might seem an initially attractive way of evaluating the consequences of any impairment that a child might have if it were born. There is, however, a difficulty with this when making decisions about embryos and that is that the alternatives for this embryo are either for it to become a child with the abnormality and all that this would entail, or not to be born at all. This is what has become known as the non-identity problem and has generated particular interest in the field of bioethics as a result of the work of Parfit.⁸¹ If the decision had been taken to use

⁷⁹ See for example Douglas, G., ‘Assisted reproduction and the welfare of the child’, *Current Legal Problems* 46 (1993): 53–74; Jackson, ‘Conception and the irrelevance of the welfare principle’; Harris, J., ‘Rights and reproductive choice’, in Harris, J., Holm, S. (eds.), *The Future of Human Reproduction: Ethics, Choice, and Regulation*, Oxford: Clarendon, 1998, pp. 5–37.

⁸⁰ See for example *Wyatt v. Portsmouth Hospital NHS Trust* [2005] EWCA Civ 1181 CA, at paras. 87 and 90.

⁸¹ Parfit, D., *Reasons and Persons*, Oxford: Oxford University Press, 1984, ch 16. For authors drawing on this work, see for example Gavaghan, C., ‘Designer donors’? Tissue-typing and the regulation of pre-implantation genetic diagnosis’, *Web*

another embryo than an affected one, a different child – with a different identity – would be born. Viewed in such terms, it might appear that considering the welfare of the child would require an assessment of the benefits of existence (with the anticipated level of resulting disability) against non-existence.

Comparisons of existence with non-existence have been considered to be inherently problematic as may be seen by looking at wrongful life claims. In such claims, as with the case of embryo selection, it is not alleged that wrongful conduct caused the disability; rather, that it caused a child with disability to be born due to opportunities to prevent this not having been offered to the parent(s). In such cases, it is the child that is the claimant, not the parents.⁸² This kind of claim was considered in the case of *McKay v. Essex Area Health Authority* (1982) which concerned a child whose mother had contracted rubella during pregnancy and had not been advised about the possible consequences for the foetus nor given the opportunity to consider an abortion. For Ackner, LJ no comparison was possible between existence and non-existence. As he put it, ‘how can a court begin to evaluate non-existence. “the undiscovered country from whose bourn no traveller returns”?’⁸³ By contrast, for Stephenson, LJ such a comparison was possible, but existence with disability was almost always preferable to non-

Journal of Current Legal Issues 3 (2004),

<http://webjcli.ncl.ac.uk/2004/issue3/gavaghan3.html> (accessed on 09/02/2012);

Kavka, G., ‘The paradox of future individuals’, *Philosophy and Public Affairs* 11 (1981): 93–112; Roberts, M., Wasserman, D. (eds), *Harming Future Persons: Ethics, Genetics and the Nonidentity Problem*, Dordrecht: Springer, 2009.

⁸² This is in contrast to cases for wrongful conception or wrongful birth which are brought on behalf of parents and where the child may or may not have disabilities. See for example *McFarlane v. Tayside Health Board* [1999] 3 WLR 1301HL; *Parkinson v. St James and Seacroft University Hospital NHS Trust* [2001] 3 All ER 97 CA.

⁸³ *McKay v. Essex Area Health Authority* [1982] QB 1166 CA, at p. 1189.

existence.⁸⁴ Despite this difference of approach, none of the judges had any real trouble in holding that wrongful life actions were inadmissible. Jackson suggests that Stephenson LJ's judgment may be preferable 'because it is ...plainly not true that the courts are *incapable* of deciding that non-existence would be preferable to (or at least no worse than) existence, since this is precisely the assessment that has sometimes been made when authorising the non-treatment of very severely disabled neonates' (Original emphasis).⁸⁵ However, the courts have generally sought to avoid the philosophical conundrum of weighing the respective benefits of existence and non-existence by claiming that they are seeking to evaluate the burdens and benefits of treatment. In other words, they do not overtly conclude that a patient 'would be better off dead' since one of the consequences of doing so would be to invite the prospect of increased challenges to the current legal position that prevents active steps being taken with the primary intention of ending life, but allows doctors in some circumstances to fail to save or prolong life.⁸⁶ So for example in the case of *Bland*, involving an adult in a persistent vegetative state and where the best interests of the patient were considered to be the guiding principle, it was said by Lord Goff that:

[T]he question is not whether it is in the best interests of the patient that he should die. The question is whether it is in the best interests of the patient that his life should be prolonged by the continuance of this form of medical treatment or care.⁸⁷

Similarly in the case of *Re A (conjoined twins)* (2000), involving the proposed surgical separation of twin girls Mary and Jodie. Ward LJ, representing the majority of the court,

⁸⁴ *Ibid.*, at p. 1182.

⁸⁵ Jackson, 'Conception and the irrelevance of the welfare principle', at 196.

⁸⁶ See for example *Airedale NHS Trust v. Bland* [1993] 1 All ER 821, Fam D, CA and HL.

⁸⁷ *Ibid.*, *per* Keith LJ, at p. 869.

considered Mary's profound disabilities and incapacity to survive independently in this way:

Given the international Conventions protecting the 'right to life' ... I conclude that it is impermissible to deny that every life has an equal inherent value. Life is worthwhile in itself whatever the diminution in one's capacity to enjoy it...Mary's life, desperate as it is, still has its own ineliminable value and dignity.⁸⁸

Despite such seemingly strong support for the merits of existence, whatever its condition, the court concluded that the separation could be performed. The situation of conjoined twins poses special difficulties, due to the need to consider the effect of the same treatment upon the best interests of two children, and the impossibility of both of their interests being regarded as paramount if they are in conflict. The judicial reasoning employed to arrive at the court's conclusion has been criticised on a number of cogent grounds.⁸⁹ However, it highlights the fact that deeming non-existence preferable to existence is not an approach that has been explicitly endorsed as an appropriate guiding principle for the judiciary, though it is hard not to see this kind of calculation as playing at least some part in assessments in fact.

Section 13(5) requires that an assessment of the welfare of an as yet unconceived child must take place, by asking treatment centres to consider the possible future for a child resulting from treatment. One option would be for them, like Ackner, LJ in *McKay*,

⁸⁸ *Re A (children) (conjoined twins: surgical separation)* [2000] 4 All ER 961 CA, at p. 1002.

⁸⁹ See for example Clucas, B., O'Donnell, K., 'Conjoined twins: the cutting edge', *Web JCLI* 5 (2002); Harris, J., 'Human beings, persons and conjoined twins: an ethical analysis of the judgment in *Re A*', *Medical Law Review* 9(3) (2001): 221–36; Huxtable, R., 'Logical separation? Conjoined twins, slippery slopes and resource allocation', *Journal of Social Welfare and Family Law* 23(4) (2001): 459–71.

to conclude that a comparison of existence with non-existence is simply not possible. If this were the extent of the consideration that a centre was bound to give, it would appear to follow that no harm to the resulting child could be demonstrated and treatment could never be refused on this basis.⁹⁰ As Gavaghan points out, ‘since it is presumably unlikely that parliamentary intent was that such a consideration should have no bearing on the decision whether to provide treatment, it seems obvious that the intention was that certain welfare considerations would lead to the refusal of such treatment’.⁹¹ As he goes on to explain, it was contemplated that ‘in certain circumstances, it is foreseeably in the interests of a potential future child to be spared existence’, or that the balance of harms and benefits in its life are such that ‘its life would constitute a harm “on balance”’.⁹²

In other words, what appears to be intended by s. 13(5), at least where the medical condition of the child is concerned, is an approach that is more akin to Stephenson, LJ in *McKay*, taking the view that there are some conditions in which life would be thought to provide such little opportunity for enjoyment of any interests that it would be preferable to avoid the foreseeable suffering of a child, in this case by avoiding its conception.⁹³ Furthermore, despite the courts’ evident reluctance to enter into such assessments in

⁹⁰ Authors differ on whether a child in such circumstances can be described as being harmed or wronged. See for example Feinberg, J., *Harm to Others* Oxford: Oxford University Press, 1984, at pp. 97–104; Feinburg, J., ‘Wrongful life and the counterfactual element in harming’, *Social Philosophy and Policy* 4(1) (1986): 145–78; Harris J., ‘The wrong of wrongful life’, *Journal of Law and Society* 17 (1990): 90–105.

⁹¹ Gavaghan, C., *Defending the Genetic Supermarket*, Abingdon: Routledge, 2007, at p. 97.

⁹² *Ibid.*

⁹³ Of course, s. 13(5) is not limited to welfare concerns relating to conditions likely to have health implications for the child. It extends to factors such as parenting environment, which creates additional difficulties in determining in what circumstances assisted reproduction treatment should be denied.

wrongful life claims, their approach has been suggested to be somewhat disingenuous when compared with other areas of judicial consideration, for example in relation to claims involving wrongful death, where it is equally impossible to embark by personal experience on an assessment of the value of existence against non-existence.⁹⁴ It also echoes the thinking in cases concerning withholding or withdrawing treatment, that existence is not always a sufficient benefit to outweigh all circumstances, although again, an explicit determination that a child or adult would be better off not existing is not the reason given for judgments.⁹⁵ However, the threshold for restricting access to treatment under the HFE Acts has the potential to be set rather lower than would be expected where decisions concern the treatment of living patients, as illustrated by the examples of congenital deafness and the single copy gene mutation for achondroplasia. These are conditions that meet the criteria for seriousness that would permit testing using PGD, and hence engage the provisions prohibiting preferential selection, but that might be thought to fall short of the kinds of expectations of extreme suffering and lack of opportunity for positive experiences that have formed the basis of consideration in the treatment of seriously ill or disabled children. Here, although the criteria of the child's life being 'intolerable' or that it would be 'demonstrably so awful' that continued treatment should not be provided have been dismissed as being separate from the test of best interests, such notions are still regarded as 'a valuable guide in the search for best interests in this kind of case'.⁹⁶ By contrast, the guidance offered on interpreting the welfare test offered by the HFEA in respect of health implications for a child suggests only that clinics should consider whether 'any child who may be born is likely to suffer from a serious medical condition' or 'circumstances that the centre considers likely to cause serious harm to any child'.⁹⁷

⁹⁴ Gavaghan, *Defending the Genetic Supermarket*, at p. 97.

⁹⁵ Jackson, 'Conception and the irrelevance of the welfare principle'.

⁹⁶ *Portsmouth Hospital NHS Trust v. Wyatt* [2004] EWCA 2247 Fam D, *per* Hedley J., at para. 24.

⁹⁷ HFEA, 8th Code of Practice.

The difficulty for parents seeking to use affected embryos is that if the genetic abnormalities the embryos have are the ones which PGD was undertaken to detect, then the condition must already have passed a threshold of seriousness, as there are restrictions on what kinds of condition can be tested for. As Jackson discusses elsewhere in this volume,⁹⁸ there is a two-tier consideration of whether PGD can be offered to a couple: first the HFEA must consider whether the condition itself meets the test of ‘seriousness’: it has to be satisfied that there is a substantial risk of a serious condition before a licence for testing of this condition can be issued.⁹⁹ This criterion must be judged by objective, non-family-specific criteria. By contrast, treatment centres, before offering PGD to a couple, must apply individualised criteria to decide whether testing for this condition for this particular couple is appropriate. This is dealt with in the HFEA Code of Practice.¹⁰⁰ These criteria include the following:

10.5 When deciding if it is appropriate to provide PGD in particular cases, the centre should consider the circumstances of those seeking treatment rather than the particular heritable condition.

10.6 The use of PGD should be considered only where there is a significant risk of a serious genetic condition being present in the embryo. When deciding if it is appropriate to provide PGD in particular cases, the seriousness of the condition in that case should be discussed between the people seeking treatment and the clinical team. The perception of the level of risk for those seeking treatment will also be an important factor for the centre to consider.

10.7 The centre should consider the following factors when deciding if PGD is appropriate in particular cases:

⁹⁸ See Chapter 4.

⁹⁹ Schedule 2 1ZA (2) HFEA 1990, as amended.

¹⁰⁰ HFEA, 8th Code of Practice, at 10.5–7.

- (a) the views of the people seeking treatment in relation to the condition to be avoided, including their previous reproductive experience
- (b) the likely degree of suffering associated with the condition
- (c) the availability of effective therapy, now and in the future
- (d) the speed of degeneration in progressive disorders
- (e) the extent of any intellectual impairment
- (f) the social support available, and
- (g) the family circumstances of the people seeking treatment.

However, the attention paid to the views of the couple and their particular circumstances is not repeated in the Code of Practice where what is at issue is making a decision whether to use an affected embryo. The guidance here is couched solely in terms of reference to the welfare of the child provision.¹⁰¹ Presumably, however, the couple's circumstances and reasons for seeking to use an affected embryo would be significant factors and, as will be discussed further, the welfare of the child criterion is not determinative under s. 13(5) of the HFEA 1990, hence permitting other factors, such as these, to be taken into account. Once again it is critical to note that the prohibitions in the legislation under ss. 13(9–11) of the HFEA 1990 rest on 'preferential' selection of affected embryos. As a result, the restrictions on the use of affected embryos are less clear-cut than they might at first appear. As I have outlined, there is the possibility that a couple could be in the position where no unaffected embryos are available, either because all embryos in a batch are affected or, more controversially, where embryos have been created and tested serially so that the couple has chosen to be in a position of only having an affected embryo. If these provisions are based on welfare of the child considerations, it could be argued that the restriction on using affected embryos should not depend on the presence or absence of other embryos that the couple could use. The condition of a child born using an affected embryo would be the same regardless of whether the couple could potentially have another child using a different embryo. However, that is not the approach that has been taken, and no discretion is permitted to allow a couple who prefer

¹⁰¹ HFEA, 8th Code of Practice, at 10.17–18.

to use an affected embryo to do so where an unaffected embryo is available.¹⁰² Welfare of the child concerns here appears definitively to trump any consideration of the views or circumstances of intending parents. They do not where the only embryo that a couple can use is one affected by a genetic disorder. Whether this is an appropriate response depends very much on the perception of the role of parental views on the kinds of children the couple feels willing and able to parent and the context in which such parental views are formed.¹⁰³ As such, it engages questions of reproductive decision-making, which will be considered in the next section.

Nevertheless, whether a treatment centre would obtain the approval of a clinical ethics committee and be prepared to exercise its discretion to enable affected embryos to be used in an individual case remains a matter of conjecture.

Reproductive choice

In Western societies, autonomy and privacy have been recognised as fundamental ethical principles and are given significant legal protection, although not, it must be said, to the exclusion of all others. Nevertheless, generally included as part of this recognition is the area of reproductive decision-making, so that as a broad proposition it can be suggested that there is an expectation that matters concerning when and whether to have children are largely regarded as matters of individual choice. As Jackson notes, people who can

¹⁰² Sections 13(9–11) HFEA 1990, as amended.

¹⁰³ See for example Krahn, T.M., ‘Regulating preimplantation genetic diagnosis: the case of Down’s syndrome’, *Medical Law Review* 19(2) (2011): 157–91; Gilbar, R. ‘Between unconditional acceptance and responsibility: should family ethics limit the scope of reproductive autonomy?’, *Child and Family Law Quarterly* 21(3) (2009): 309–35.

conceive children without medical assistance can do so ‘without any external scrutiny of the merit or otherwise of their decision’.¹⁰⁴

However, although we may live in a time in which the notion of individual rights is pervasive, the extent to which reproductive rights exist and may be enforced is by no means uncontentious. As Brazier suggests:

Few might dissent from a rhetorical assertion that men and women have a right to found a family. Begin to debate what that right entails and who enjoys it and dispute resurfaces.¹⁰⁵

The reasons that have been put forward for claiming that there is a presumption of non-interference in decisions about founding a family are various.¹⁰⁶ Robertson, for example, has described it as follows:

The moral right to reproduce is respected because of the centrality of reproduction to personal identity, meaning and dignity...Because of this importance the right to reproduce is widely recognised as a prima facie moral right that cannot be limited except for very good reason.¹⁰⁷

¹⁰⁴ Jackson, ‘Conception and the irrelevance of the welfare principle’, at 177. Even so, they may not be exclusively matters for the individual so that, for example, the criminal law has a role to play in matters such as abortion, incest and the legal age of consent to sexual intercourse.

¹⁰⁵ Brazier, M., ‘Regulating the reproductive business?’, *Medical Law Review* 7 (1999): 166–93, at 168.

¹⁰⁶ For more detailed discussion, see for example N. Priaux, ‘Rethinking progenerative conflict: why reproductive autonomy matters’, *Medical Law Review* 16(2) (2008): 169–200.

¹⁰⁷ Robertson, J., *Children of Choice*, Princeton, NJ: Princeton University Press, 1994, at p. 30.

For others, such as Jackson, this right is grounded more specifically on two different aspects of privacy:

First, that interfering with a particular individual's decision to conceive a child would usually involve violating their bodily integrity and sexual privacy. The second and I would argue equally important reason for respecting people's conception choices is that the freedom to decide for oneself whether or not to reproduce is integral to a person's sense of being, in some important sense, the author of their own life plan.¹⁰⁸

Authors such as Laing and Oderberg on the other hand suggest that autonomy and decisional privacy should not be regarded as trump cards where reproductive decisions are concerned. They argue that:

a proper evaluation of AR [assisted reproduction] and of the relevance of welfare will be sensitive not only to the rights of 'commissioning parties' to AR but also to public policy considerations. We argue that AR has implications for the common good, by involving matters of human reproduction, kinship, race, parenthood and identity.¹⁰⁹

The thrust of their argument is directed at the use of assisted reproduction in itself as a means of creating children and suggests a number of grounds to support restrictions on individual choice, welfare of resulting children being one of them. However, even they concede that 'There are legitimate general principles against state interference in

¹⁰⁸ Jackson, 'Conception and the irrelevance of the welfare principle', at 177.

¹⁰⁹ Laing, J.A., Oderberg, D.S., 'Artificial reproduction, the "welfare principle", and the common good', *Medical Law Review* 13(3) (2005): 328–56, at 328.

reproductive decision-making; these derive both from anti-eugenicist considerations' and from human rights principles.¹¹⁰

The importance of reproductive decision-making may seem to be protected by the human rights principles contained in the European Convention on Human Rights and Fundamental Freedoms, particularly in Article 12, the *right to marry and to found a family* and Article 8, the *right to respect for private and family life*, although as UK case law, such as *Evans* and *Briody* demonstrate, these rights are by no means absolute.¹¹¹

It can be suggested that what is really being protected by the ECHR is a negative right, a liberty, to seek to found a family without outside interference, but that it does not go so far as to accord a positive right: a right to assistance. This kind of thinking was clearly evident in the judgment of Hale, LJ in the case of *Briody*, concerning whether there could be an award of damages to enable a surrogacy arrangement to be undertaken:

While everyone has the right to try to have their own children by natural means, no-one has the right to be provided with a child.¹¹²

The reasons for regarding reproductive choice as only a liberty are diverse but, along with the kinds of public interest and human dignity concerns referred to by Laing and Oderberg, include the recognition that to do otherwise might be to commit the state to furnishing the means of reproduction if they were not available otherwise to the individual or couple: a commitment that could not be fulfilled without significant material, technical and financial resources. Nevertheless, even if this more limited

¹¹⁰ *Ibid.*, at 330.

¹¹¹ *Evans v. Amicus Healthcare* [2004] EWCA Civ 727, [2004] 2 All ER 309 (HL),
Briody v. St Helens and Knowsley Area Health Authority (Claim for Damages and Costs) (2001) 62 BMLR 1 CA.

¹¹² *Briody v. St Helens and Knowsley Area Health Authority* (Claim for Damages and Costs) (2001) 62 BMLR 1 CA, para. 26.

approach is adopted, there remains the question whether the regulation of an available means of founding a family, such as assisted reproduction, can be seen as an acceptable restriction on the liberty of individuals. After all, it could be argued that the restrictions on the provision of treatment services in the HFE Acts interfere with the possible choices of the medically infertile, those whose social circumstances lead them to seek to use assisted reproductive techniques, or those who for medical reasons wish to use IVF and embryo testing in order to make certain choices regarding the genetic make-up of any child they will have. As such, this may in itself be regarded as a restriction on reproductive liberty.¹¹³

So far the approach that has been taken both by British courts and by the European Court of Human Rights has been to allow such restrictions to be imposed in principle without much comment, although the nature of particular restrictions may still need to be justified. So in the case of *Briody*, it was said in relation to the Article 12 right in the European Convention on Human Rights and Fundamental Freedoms that:

The right to marry and found a family are freedoms which should not be arbitrarily restricted, for example by preventing prisoners from marrying; this may well preclude placing arbitrary or disproportionate restrictions upon access to the reproductive services which are generally available. But that is quite different from having a right to be supplied with a child (or a spouse).¹¹⁴

Similarly, in the European Court of Human Rights in the case of *Dickson*, restrictions imposed by the Secretary of State on access to assisted reproduction by a prisoner and his wife were said to be disproportionate to the legitimate aims of the state when dealing

¹¹³ Discussed in Jackson, 'Conception and the irrelevance of the welfare principle', at 184–5.

¹¹⁴ *Briody v. St Helens & Knowsley AHA (Claim for Damages and Costs)* (2001) 62 BMLR 1 CA, *per* LJ Hale, para. 26.

with offenders.¹¹⁵ Although specifically concerned with the right to access IVF treatment during imprisonment, the case contains some interesting comments on the extent to which restrictions may be imposed. It was held by the majority of the European Court of Human Rights that Article 8 of the European Convention on Human Rights and Fundamental Freedoms was engaged, in that the complainants' right to respect for their private and family lives incorporated rights to respect for their decision to become genetic parents. Prisoners retained Convention rights on imprisonment and any restrictions must be justified in each case; such justification could not be based solely on what would offend public opinion. However, in respect of welfare of the child concerns it was said that:

The Court is prepared to accept as legitimate, for the purposes of the second paragraph of Article 8, that the authorities, when developing and applying the Policy, should concern themselves, as a matter of principle, with the welfare of any child: conception of a child was the very object of the exercise. Moreover, the State has a positive obligation to ensure the effective protection of children.¹¹⁶

However, it went on to say that the state could not go so far as to prevent parents from conceiving a child in these circumstances. UK policy was held to have placed an inordinately high burden on the complainants to demonstrate that deprivation of the opportunity to undertake assisted reproduction might prevent conception altogether, and that their circumstances were 'exceptional'. That did not allow a balancing of competing individual and public interests, nor a proportionality test to be applied, as required by the Convention. The policy was not embodied in primary legislation, competing interests had never been weighed, and the issues of proportionality had never been assessed by Parliament.¹¹⁷ In the absence of such an assessment, the policy was seen as falling

¹¹⁵ *Dickson v. UK* (ECHR 2007) (Application no. 44362/04).

¹¹⁶ *Ibid.*, para. 76.

¹¹⁷ *Ibid.*, paras. 77–85.

outside any acceptable margin of appreciation. The complainants were awarded €5,000 by way of damages for frustration and distress.

Nevertheless, the general principle that a regulatory framework may be imposed on assisted reproduction services has so far not been successfully challenged in the ECHR, and there are those who have doubts about the utility of human rights principles as a means of protecting people's choices in assisted reproduction.¹¹⁸ Furthermore, whether people should have a right not only to choose to try to have children, but to attempt to determine the characteristics of their children, adds another dimension to the meaning and scope of decisions concerning reproduction. As Robertson puts it:

[c]hoices about who may conceive, bear or rear a child are distinct from choices about the conduct that occurs in the process of conceiving, bearing and rearing. In other words, arguably, the freedom *to* procreate is [would be] distinct from the freedom *in* procreation.¹¹⁹ [original emphasis]

As has been made clear, one of the principal grounds for refusing treatment using embryos tested and discovered to have specific genetic conditions is the welfare of the child. It is implicit in the HFEA 1990, ss. 13(9–11) conditions and it appears to have been given overriding importance where what is at issue is the preferential selection of an affected embryo. However, somewhat paradoxically, where the child welfare principle is explicitly set out, in s. 13(5), it is not stated to be of paramount importance: it is a matter only that must be taken into account by treatment centres. While one of the major factors to be considered in the welfare assessment is undoubtedly the medical condition of a child resulting from treatment covered by the HFE Acts, the approach taken by s. 13(5)

¹¹⁸ See for example Eijkholt, M., 'The right to found a family as a stillborn right to procreate?', *Medical Law Review* 18(2) (2010): 127–51.

¹¹⁹ Robertson, J.A., 'Procreative liberty and the control of conception, pregnancy, and childbirth', *Virginia Law Review* 69 (1983): 405–65, at 410.

does allow other factors, such as the views and circumstances of couples, and more broadly, their reproductive freedom, to be weighed against it.

One possible argument suggests that depriving people of the ability to choose to have children with genetic abnormalities is permissible as this is simply not the kind of reproductive choice that *should* be protected. For example, Harris has stated that ‘it is wrong to bring avoidable suffering into the world’.¹²⁰ Two widely accepted ethical principles are those of beneficence (to do good) and non-maleficence (to avoid causing harm). In the 1970s, Beauchamp and Childress popularised an approach combining these with respect for autonomy and justice, which went on to strongly influence healthcare ethics.¹²¹ While the ‘four principles’ approach they championed has been subjected increasingly to a more critical evaluation,¹²² nevertheless the importance of a desire to do good and avoid harm as general touchstones for ethical behaviour must surely remain. Difficulties inevitably arise, however, in the application of such principles in practice, such as in making decisions about the kinds of children one should seek to have.

In the context of human reproduction, Savulescu has described a principle of ‘procreative beneficence’ as follows: ‘couples...should select the child, of the possible children they could have, who is expected to have the best life, or at least as good a life as

¹²⁰ Harris, J., ‘Is there a coherent social concept of disability?’, *Journal of Medical Ethics* 26 (2000): 95–100, at 96.

¹²¹ This approach was popularised by Beauchamp, T.L., Childress, J.F., *Principles of Biomedical Ethics*, 6th edn, New York: Oxford University Press, 2008. See for example Gillon, R., ‘Medical ethics: four principles plus attention to scope’, *British Medical Journal* 309(6948) (1994): 184–8.

¹²² See for example Campbell, A., ‘The virtues (and vices) of the four principles’, *Journal of Medical Ethics* 29 (2003): 292–6; Walker, T., ‘What principlism misses’, *Journal of Medical Ethics* 35 (2009): 229–31.

the others'.¹²³ While making some concessions to the degree of prediction that is possible he concludes 'Even if we cannot know the value of a whole life, we can know that conditions are good or bad, and this provides a reason to prefer to bring children into existence without those conditions'.¹²⁴ Nevertheless, he also makes a substantial limitation on his argument, saying 'If, in the end, couples wish to select a child who will have a lower chance of having the best life, they should be free to make such a choice'.¹²⁵ He therefore ultimately places a higher priority on respecting the wishes of prospective parents in respect of their reproductive choices than on protecting the welfare of the child that might be born. He distinguishes between what might be a virtuous argument and what should be a legal restriction. This is an important distinction. In a similar vein, the HCSTC considered that 'Even strong ethical arguments that there should be constraints on reproductive choice do not necessarily mean that legislation should provide that check' and quoted with approval a line from a contributor to their on-line consultation 'there is an important difference between disapproving and disallowing'.¹²⁶

There may be some conditions for which it is difficult to argue that positive experiences for a child outweigh negative ones. One often used example is that of Tay–Sachs, a genetic disorder which causes death in early childhood, preceded by increasingly debilitating and distressing physical and mental decline, and for which there is no cure.¹²⁷ Other conditions, however, will inevitably be much more contentious. As Scott explains:

¹²³ Savulescu, J., 'Procreative beneficence: why we should select the best children', *Bioethics* 15 (2001): 413–26, at 415.

¹²⁴ Savulescu, J., 'In defence of procreative beneficence', *Journal of Medical Ethics* 33 (2007): 284–8, at 284.

¹²⁵ Savulescu, 'Procreative beneficence', at 425.

¹²⁶ HCSTC, Fifth Report of Session 2004–5, *Human Reproductive Technologies and the Law*, vol.1, para. 112

¹²⁷ National Institute of Neurological Disorders and Stroke (NINDS), Tay–Sachs disease information page, www.ninds.nih.gov/disorders/taysachs/taysachs.htm (accessed on 11/11/2011).

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as we move away from the extreme and rare case, judging seriousness is very difficult. It is made more complex by the potentially competing perspectives – parental, medical and those of the impaired – on this issue.¹²⁸

She goes on to say:

In some cases, although a possible child may have the prospect of a reasonable quality of life, his impairments may still implicate his parents' interests in reproduction in serious ways; he might have a significant mental impairment or serious health problems requiring repeated hospitalisation with an uncertain future.¹²⁹

Her discussion concerns whether parents should be able to seek PGD, in terms of the assessment of a condition being serious enough to merit testing and the consequent rejection of embryos found to have it. However, it is also applicable to the situation where a couple seeks to use embryos that have been tested and found to have genetic disorders or to be at risk of developing particular medical conditions. Here too the rights and interests of the couple are engaged along with those of a future child. Balancing these potentially competing considerations raises profound questions about legitimate boundaries upon reproductive decision-making. Scott's conclusion is that 'in cases of reasonable disagreement about seriousness, parental views and interests should carry the most weight'.¹³⁰ Of course the immediate difficulties return – what is a 'reasonable quality of life' or 'reasonable disagreement about seriousness'? In cases where agreement cannot be reached between couples and treatment providers over the proposed use of

¹²⁸ Scott, R., 'Choosing between possible lives: legal and ethical issues in preimplantation genetic diagnosis', *Oxford Journal of Legal Studies* 26(1) (2006): 153–78, at 164.

¹²⁹ *Ibid.*

¹³⁰ *Ibid.* This argument is made in more detail in Scott, R., 'Prenatal screening, autonomy and reasons: the relationship between the law of abortion and wrongful life', *Medical Law Review* 11(3) (2003): 265–325.

affected embryos, resort may be had to the courts in an attempt to resolve them. The likelihood of success for couples may, however, be limited.¹³¹ The issue remains, however, that no concession is made to considerations of reproductive autonomy for a couple that wishes to use an affected embryo rather than an unaffected one, where the couple has both available.

Conclusion

Questions have been raised about the suitability and applicability of a welfare of the child standard where what is under consideration is the possible conception of a child rather than the welfare of a child who has been born. Although there are some circumstances in which it might be argued that a future child's life would have so few redeeming features that it might be considered better to avoid this by not seeking to implant an affected embryo, the extent to which this would be true in many cases is a matter about which opinions may differ sharply. Where certain conditions, such as congenital deafness or achondroplasia are concerned the scope for interference with potential parental choice becomes particularly troubling. The application of the welfare principle to the selection of embryos is undoubtedly problematic, but interpreting it in the only way that is practicable still leaves room to suggest that overriding the views of potential parents on the basis of child welfare, where they wish to proceed with treatment using affected embryos, should be undertaken with extreme caution.

The clear intention of the amendment of the treatment licensing provisions of the HFEA 1990 was to prevent potential parents from exercising a choice to select for disability. As a result, there is now no discretion to allow a couple to choose to use an affected embryo where there is at least one unaffected embryo available. Despite this,

¹³¹ See for example, the discussion in Bell, 'Human Fertilisation and Embryology Act 2008', *Web JCLI* 1 [2009], <http://webjcli.ncl.ac.uk/2009/issue1/bell1.html> (accessed on 09/02/2012).

there is in fact no absolute prohibition on using an affected embryo for treatment if there is no unaffected embryo that could be used instead. This may apply even where a couple has deliberately sought to engineer the situation by serial creation and testing of embryos, so as to circumvent the provisions on preferential selection in ss. 13(9–11) of the HFEA 1990. However, the use of any embryo for treatment remains subject to the overarching principle of child welfare set out in s. 13(5) HFEA 1990, as amended. Given that this is the case, there are reasons to doubt whether the inclusion of the embryo selection restrictions was strictly necessary if, as seems, clear the justification for the more specific provisions is also child welfare. Simply relying on s. 13(5) would have allowed discretion to be exercised in respect of the use of a particular embryo, regardless of the availability of other embryos that the couple could use. That would in many ways appear to be a more logical approach to have taken, since the welfare of a particular child, judged on its genetic condition, is not usually dependent on the absence or presence of alternative children that a couple could have.¹³² Welfare decisions could therefore have been made on a case by case basis where any couple sought to use an embryo which had a genetic condition placing it at risk of, or with a certainty of developing, a serious medical condition. Such decisions might well have remained contentious and the application of the welfare principle no easier a task. Nevertheless, as it stands, discretion to allow the use of embryos has been curtailed absolutely in some situations.

As such it may be concluded that the real effect of the new provisions is in the signals that it sends about the kind of decisions people should make where there is a possibility of having certain kinds of children. In fact, the aims of the legislation go further and deem certain choices unacceptable and hence prohibited. This brings into play what may be termed expressivist objections. The most common arguments based on expressivist grounds concern choices to select against disability. Here it has been

¹³² An exception might be where a child has a genetic condition for which PGD might be used to create a ‘saviour sibling’ to provide material for donation. This however concerns the welfare of a born child rather than the welfare of the yet-to-be conceived child, which is at issue here.

contended that selection for reproductive purposes to *avoid* the conception or birth of people with disabling medical conditions can cause ‘offence and hurt to people currently living with the kinds of conditions screened for’.¹³³ A frequent counter to such objections to PGD is that allowing people to have the choice to avoid having children with disabilities does not necessarily devalue people who have such disabilities.¹³⁴ However, legislating that choices to have particular children are unacceptable, based on their predicted medical condition, may have more force in engendering these kinds of objections. A couple may wish to avoid having a child with physical or mental illness for many reasons, which do not necessarily imply a value judgement about people who have such conditions.¹³⁵ However, for the law to provide that couples should not be able to choose to create a child with genetic abnormalities in some circumstances seems to come rather closer to a state endorsed view that certain kinds of lives are not worth living by mandating that the creation of such lives should be avoided, at least where other lives that would be considered to have greater opportunities could be brought into being. In doing so, it restricts reproductive freedom with the purported aim of child protection. If it is accepted that there are family circumstances which permit a couple legitimately to be permitted to seek to avoid having children with disabilities, it may be arguable that in some cases at least, having children with specific conditions that may be regarded as disabling would be a legitimate choice for the couple concerned. Notwithstanding the approach of the new legislation, there may be some scope for such preferences to be achieved, but the interpretation of child welfare based provisions, through the HFEA, treatment centres and clinical ethics committees, will be critical. The likelihood of such cases arising in practice may be small, but nevertheless they raise significant issues.

¹³³ Edwards, S.D. ‘Disability, identity and the “expressivist objection”’, *Journal of Medical Ethics* 30 (2004): 418–20, at 418.

¹³⁴ See for example Gavaghan, C., ‘Right problem wrong solution: a pro-choice response to “expressivist” concerns about preimplantation genetic diagnosis’, *Cambridge Quarterly of Healthcare Ethics* 16 (2007): 20–34; Edwards, ‘Disability, identity’.

¹³⁵ For a discussion of this issue see Gavaghan, *Defending the Genetic Supermarket*, at pp. 110–14.

