

The reasonably happy child

On the moral evaluation standard for access to assisted reproduction

Master Thesis Applied Ethics

Utrecht University, June 2011

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Preface

After graduating from medical school, now some twenty years ago, I went to work in the fertility department of an academic hospital. In charge of doing the intake and evaluation of patients that presented themselves with fertility problems, I was instructed to make inquiries into the stability of the relationship of the presenting couple - preferably they were to be married- as this was considered to be an important criterion for allowing them access to whatever reproductive service that was required. Although doing as I was instructed, it was often with a feeling of great discomfort for having to invade the other persons privacy and uncertainty as to the relevance of the inquiry.

Things have moved on since then and at least being married is no longer considered to be a prerequisite for having access to assisted reproduction. However, the underlying idea, that it is important to take account of factors, whatever they may be, that might negatively influence the welfare of a child born as a result of assisted reproduction still is and has always been considered to be very important.

After quite a few years of experience in the field of reproductive medicine and in the field of 'becoming a parent' myself I have learned at least two things: 1. it is extremely difficult to deny someone else the opportunity to become a parent, if you are holding the key to the realization of this opportunity, and 2. it is extremely difficult to deny the intuition that you sometimes just don't want to be responsible for helping to bring a child into existence when you 'know' that this child will face great difficulty in life.

Thus, if we decide to follow up on this intuition, we better make sure our reasons to do so are well grounded.

1 Introduction

Consider the following case: a woman, Lucy, presents herself with a request for donor insemination. Her female partner already has conceived twins through IVF with donor semen after donor insemination had failed. The whole treatment and pregnancy have taken their toll and she no longer dares to go through the whole program again, but the couple still desires to extend their family with an additional child. Lucy suffers from a hereditary form of eye disease. Although she was born with normal eyesight, she has gradually become blind during the early years of her life. Any child she would have has a 50 % chance of inheriting this disease. Even if it were possible through pre-implantation or prenatal diagnosis to determine if a child would be affected, she does not wish to undertake such tests. She does not want to resort to finding a donor herself and apply self-insemination because of safety considerations with regard to transmission of infectious disease and because she prefers anonymity (this was before the prohibition of anonymous donations). She herself and other members of her family suffer from this disease and experience their lives as thoroughly worthwhile. After due consideration and extensive consultation the request was denied. Now, looking back, I again cannot help but wonder if it was the right decision. Had she been in a heterosexual relationship, she would most likely have had a child. If this child would have been affected, it might have had a reasonably happy life, despite all the difficulties it would experience due to being blind.

However, physicians who are in the 'business' of providing reproductive technologies, may also, as in the above case, disagree with parents 'to be' about what would be in the best interest of their future child. When welfare considerations of such a child yet to be conceived are to be taken into consideration, they may come to feel, that it would be better for this child not to be born at all. As such, the fertility specialist feels a dual responsibility both towards the prospective parents and the future child and this responsibility is widely acknowledged. As stated by the ESHRE Task force on ethics and law: *"The physician carries joint responsibility for the welfare of the child because of his or her causal and intentional contribution to the parental project. The physician must take into account presently known risk factors for the welfare of the future child. To avoid*

*prejudice, arbitrariness and discrimination, objective evidence must be sought to be able to offer good reasons for refusing assistance”.*¹

In addition to this dual responsibility towards prospective parents and their future child, the physician also has to deal with his own personal moral standards, which all together requires the complex task of finding a proper balance between reproductive freedom, harm to offspring and professional autonomy.²

How is the welfare of the future child to be evaluated? Currently the dominant view is that in order to fulfil the responsibility to the future child, health care providers should rely on the standard of reasonable welfare. This reasonable welfare standard or principle is formulated as follows: *“The provision of medical assistance in procreation is acceptable when the child born as a result of the treatment will have a reasonable happy life”.*³ This principle is considered to be intermediate between two other evaluation standards, that of ‘minimal welfare’ and that of ‘maximum welfare’. In short, minimal welfare implies that assisted procreation is unjustified only when the child that is brought into existence is expected to have a life not worth living. Maximum welfare implies that assisted procreation can only be justified under ideal circumstances.⁴ By adopting a position somewhere in between these two standards, the reasonable welfare principle *“avoids the counterintuitive judgements of the two other principles and simultaneously conforms more closely with the way we look at procreation and parental responsibility in ordinary life”.*⁵

Although a consensus appears to have been reached at the level of professional organisations for fertility specialists, both in the Netherlands and at a European level⁶, having to take the welfare of the future child into account and how far this responsibility goes is subject of a debate about welfare consideration in the light of assisted reproductive technologies that has been going for over at least two decades.

The aim of this thesis is to examine in what ways the reasonable welfare standard is problematic for the assessment of access to ART. The approach to this question is two-fold. On the one hand, it will evaluate problematic aspects of the standard that relate to

¹ ESHR Task Force 2007

² Robertson 2004

³ Pennings 1999

⁴ *ibid*

⁵ *ibid*

⁶ Modelprotocol NVOG 2010, ESHRE Taskforce 2007

its application in practice, on the other hand it will examine if a welfare standard is in itself problematic from a more fundamental philosophical- ethical perspective.

As to the first aim, the underlying assumption that it is possible to define, measure or predict a 'reasonable happy life' can be questioned. Much of this debate has focused on empirical questions that relate to the severity and likelihood of harm occurring. Of a more fundamental nature is the criticism that 'welfare-of-the child' considerations for assisted reproduction in general represent an unjustifiable intrusion on procreative autonomy or liberty. This debate focuses on the tension between procreative liberty and professional responsibility.

The reasonable welfare standard can also be challenged from a different perspective. The intuition behind the principle is that we feel that it is wrong to assist in bringing a child into the world under certain conditions, because we have well reason to suspect that *this child* is likely to have an awful life. The wrongness rests on the so-called person-affecting intuition that "*what is bad must be bad for someone*".⁷ Contemplating the wrongness of an action, we are thus inclined to think that it must in some way be connected to another person having been made worse of or harmed. This person-affecting intuition is however challenged by the 'non-identity problem', a problem that arises uniquely in connection with future persons, persons who do not exist at the time the act under consideration is performed and who's coming into existence fully depends upon that very same act.⁸ If some acts of assisted reproduction can not be judged wrong because they are 'bad' for 'no one', what than can be the grounds for considering these acts wrong?

In chapter 2 an overview will be provided of ART associated risks, evaluation standards for welfare of the child and current regulation policies. In chapter 3 the above mentioned problematic issues relating to the reasonable welfare standard will be discussed. In the concluding chapter I will elaborate on the possible implications of these problems.

⁷ Parfit 1987, p.363

⁸ Roberts & Wasserman, 2009

2 Assisted reproductive technologies and welfare considerations

2.1 Assisted reproductive technologies and risks of harm to offspring

The collective noun Assisted Reproductive Technologies (ART) is used to address all treatments that include in vitro handling of human gametes (eggs and sperm) and embryos to establish a pregnancy. Many of these techniques were initially introduced for the treatment of infertility. It is estimated that one in six couples experience infertility in some form at least once during their reproductive lifespan.⁹ Since the birth of Louise Brown, the first child to be born after in vitro fertilization, in 1978, over 3.75 million babies have been born worldwide.¹⁰ Assisted reproduction accounts for an increasing proportion of all births; for example among those European countries from which data are available, approximately 1.7% of all births each year result from assisted reproduction procedures.

Although the focus in this thesis is on the risk of harm to offspring, it is important to realize that for the women involved these techniques often are also not without risk (such as ovarian hyperstimulation syndrome and multiple pregnancies) and that these treatments can be extremely burdensome, both physically and mentally. The point I want to make here is that a decision to refer to assisted procreation is most often not taken lightly and without due consideration by the prospective parents.

Considering the welfare of the future child after ART, there are numerous factors that may have implications.

The first group of potential risk factors are those that are directly related to the treatment or the techniques that are applied. One of the more serious health problems associated with treatments that involve ovarian stimulation or transfer of multiple embryos are those related to multiple pregnancy, such as premature birth and intra-uterine growth retardation. Over the last decade concerns have also been raised as to the increased chance of birth defects in children born after IVF and ICSI. A position statement issued by ESHRE states that children born after ART have a twofold increase in risk for a birth defect, relative to the risk of a birth defect in all children born of 3%.

⁹ Current prevalence of infertility lasting for at least 12 months averages 9% worldwide for women aged 20-44. www.eshre.eu/ESHRE/English/Guidelines-Legal/ART-fact-sheet/page.aspx/1061

¹⁰ www.eshre.eu/ESHRE/English/Guidelines-Legal/ART-fact-sheet/page.aspx/1061

Since a similar increased risk has been reported for subfertile couples who get pregnant spontaneously after a prolonged period of time, this increased risk seems thus mainly to be due to parental characteristics from the infertility status and not to the treatment given.¹¹ The risks that fall into this 'treatment-related' category will normally be considered to determine when a treatment will be deemed safe enough in general. Once it is decided after sufficient research that a treatment can be deemed safe enough in terms of medical risks, these risks only rarely provide a reason to refuse treatment in an individual case.

Of more importance for the use of a welfare standard are risks of transmission of a genetic or infectious disease. If a couple know that they are carriers of a serious genetic condition, or one of them is affected by one, they will know before a child is conceived that it has either a 50% or a 25% chance of inheriting that condition. The chance that an infectious disease such as HIV is transmitted to a child depends upon a number of factors, such as which parent is affected and whether steps are taken to limit the chance of transmission, either through sperm washing (if the male partner is affected) or through obstetric management (when the female partner is affected).

Then there are risks associated with psychosocial factors. Physicians may sometimes fear risk of harm to a future child when there is reason to doubt the child-rearing competencies of the prospective parents. This may be the case when there is a history of child abuse or neglect, when there is a conviction for a child-related offence or when a child or children have been taken into the care of a local authority. Other potentially harmful conditions include alcohol or drug abuse and psychiatric problems.

Furthermore, in addition to smoking and alcohol, obesity as a life-style related factor is increasingly recognized not only as a prognostic factor for treatment success, but also as a risk factor for the welfare of the child.¹²

Many of the mentioned risk factors are not unique to assisted reproduction but occur in cases of natural reproduction as well. Some may be more easily quantified than others and in many cases there remains a great deal of uncertainty as to the potentially harmful effects of any of these factors.

¹¹

www.eshre.eu/binarydata.aspx?type=doc&sessionId=z2sfez55lolsgabthuiqro55/Birth_defects_position_papers.pdf; accessed on 24-5-2011.

¹² ESHRE Task Force 2010

Some of the applications of ART also raise questions that relate to the potentially harmful effects that a child might experience from being genetically unrelated to one or both parents, from being raised in a setting departing from the traditional heterosexual married couple or from being 'made up by design'. These issues arise because many techniques in assisted reproduction that were initially introduced as a means to overcome infertility, are nowadays also used to assist procreation in cases that are not infertility related, like donor insemination for lesbian couples. The development of the technique of in vitro fertilization, initially meant to overcome infertility due to a blockage of the fallopian tubes, can also be used for procreation in postmenopausal women and for so-called shared motherhood in lesbian couples. The development of techniques for cryopreservation of embryo's and eggcells has opened up the possibility of donation and, more recently introduced, can now be offered to women to allow them to preserve their fertility and delay their reproductive choices for social reasons. Pre-implantation genetic diagnosis (PGD), developed to prevent the transmission of serious genetic diseases, like Huntington's disease and cystic fibrosis, can (although not currently allowed in the Netherlands) be used, for instance, for sex-selection for non-medical reasons or (science fiction yet) to enhance the genetic make-up of the child.

If physicians have to take the welfare-of -the-future child into consideration when providing access to ART, the standards by which these considerations might be evaluated and how they are incorporated in current practice will be discussed in the next two sections.

2.2. Evaluation standards for the welfare of the future child

Three evaluation standards can be used to assess whether offering ART is acceptable.

The maximum welfare standard¹³ is based upon the idea that one should not knowingly and intentionally bring a child into the world in less than ideal circumstances. It thus places a significant responsibility on those who assist in the creation of children to restrict their cooperation to those cases which maximizes the welfare of the child and ensure that any child born has a good chance of living a happy and fulfilled life and is not disadvantaged in any foreseeable way. This approach considers a child's welfare to be of

¹³ Also referred to as maximum welfare principle

paramount importance and applied in a very strict sense this would probably mean that almost everyone would have to be excluded, beginning with the '*poor, handicapped, obese, workaholics and /or old*'.¹⁴ More often, however, the maximum welfare standard is ceased by those who oppose procreation in settings that deviate from the traditional heterosexual family, because they consider this to be representative of the ideal situation, "the gold standard".¹⁵ However, opposition to parenthood in same sex relations and even single parenthood has shifted towards becoming more accepted over the last two decades, due to empirical data on the welfare of children growing up in such settings.¹⁶ Thus, perception of ideal circumstances may change quite rapidly over time and may not serve as a very reliable criterion. On the other hand, those whose opposition against deviation from the ideal situation is based on their particular (religious) worldview, will not be convinced by empirical evidence on the welfare of the child.¹⁷ Either way, adhering to the maximum welfare standard, be it based on consequentialist or on deontological arguments, is difficult to defend, because it leaves no room whatsoever for the autonomy of the prospective parents.

The minimum threshold principle goes to the other extreme. Doctors should withhold treatment only when the expected quality of the child's life would fall below a minimum threshold of acceptability. On a strict interpretation, this principle only applies to cases where the expected life of a child would be so bad that it would not be worth living, the so-called wrongful life cases.¹⁸ This approach places overriding importance upon the autonomy of the prospective parents and might lead us to accept treatment requests that are very counter-intuitive. It is difficult to give examples of conditions that would definitely fall into this category of being so wretched that non-existence would be preferable, but we might think of cases where chronic pain combined with severe mental retardation would cause the child to be unable to develop any compensating interests.¹⁹ Lesch-Nyhan syndrome and Tay-Sachs disease are often mentioned in this context.^{20,21}

¹⁴ Pennings 1999

¹⁵ Pennings 2011

¹⁶ Golombok 1998

¹⁷ *ibid*

¹⁸ the term wrongful life is in fact a term used to refer to legal cases in which someone, typically a health care provider is sued by (the legal guardian of) a severely handicapped child for failing to prevent the child's birth.

¹⁹ Freeman 1997

²⁰ Buchanan et al.2000, p.233

The reasonable welfare standard was introduced as an intermediate standard, because it avoids some of the counterintuitive judgments, implicated by the other two standards. In its original formulation by Pennings the rule to evaluate the application of new reproductive technologies is stated as follows: “ *The provision of medical assistance in procreation is acceptable when the child born as a result of the treatment will have a reasonably happy life*”.²² This approach requires those providing assisted reproduction services to satisfy themselves that any child born of treatment that they provide will have at least an adequate future, cared for by a ‘good enough’ family. On Pennings’s common sense account of welfare, a decent welfare level means having the “*abilities and opportunities to realize those dimensions and goals that in general make human lives valuable*”. Under the reasonable welfare standard considerations for the welfare of the child as well as the autonomy of the prospective parents are taken into account. The reasonable welfare principle, although initially not formulated as such, has come to be considered to be synonymous to the implication that assisted procreation is morally wrong when there is “ a high risk for serious harm” ²³ and the two descriptions are used interchangeable.

2.3. Regulation of access to ART and the reasonable welfare principle

Amongst Western European countries, reproductive policy in the Netherlands can be classified as ‘permissive’, meaning that there are only light policy instruments like licensing procedures to regulate professional autonomy and patient access.²⁴ Unlike the UK, where a welfare provision was already incorporated in legislation regulating assisted reproduction in 1990 ²⁵, there is no legislation that instructs physicians that they should take the welfare of children who may be born as result of ART in to account.

²¹ These are genetic metabolic disorders that cause deterioration of physical and mental abilities within the first year. Children with Tay-Sachs disease die around the age of four, children with Lesch-Nyhan may reach adulthood.

²² Pennings 1999

²³ De Wert 1999

²⁴ Engeli 2009

²⁵ Human Fertilisation and Embryology Act 1990; section 13(5) read: “A women 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 a father) and of any other child who may be affected by the birth”. The law was amended in 2008, where ‘including the need for a father’ was replaced by ‘including the need of that child for supportive parenting’.

However, such a responsibility can be deduced from the legal requirement of the physician to act according to the professional standard, which includes not only taking account of the individual patient but also of the interests of third parties, i.c. the future child.²⁶ Based on the European Convention for Human Rights art 8 (the right to respect for private and family life) and 12, (the right to marry and found a family) a right to treatment for infertility cannot be claimed, but only a right not to be interfered with by the state or other parties.²⁷ On the other hand, excluding certain groups of patients, like lesbian or single women, cannot legally be justified because of the legal right of equal treatment.

In 2004 research was conducted on psychological, ethical and legal aspects of access policy for assisted reproduction in the Netherlands, which resulted in recommendations for clinical practice, advocating the reasonable welfare standard as the most appropriate criterion to evaluate the welfare of the child.²⁸ At a European level likewise recommendations were issued in 2007, departing from a reasonable welfare standard.²⁹ In 2010 the NVOG, (the Dutch Association for Obstetricians and Gynecologists) has followed suit and issued a guideline concerning possible moral contra-indications for assisted reproduction based on the reasonable welfare standard. This guideline acknowledges the dual responsibility of health care providers in reproductive medicine. Essential elements are the following: 1. A decision not to treat is to be considered an exception to the norm. 2. the physician is not expected to actively pursue an investigation into factors that might pose a moral contra-indication for treatment. 3. in cases of uncertainty the case is to be referred and deliberated in a multi-disciplinary committee in a transparent way. 4. the treating physician carries the final responsibility for the decision.

²⁶ Modelprotocol NVOG, 2010

²⁷ Bolt 2004, p.60

²⁸ *ibid*, p. 62

²⁹ ESHRE Task Force on Ethics and Law 13, 2007

3 Analysis of problematic issues related to the reasonable welfare standard

3.1 Reasonable welfare: what does it mean?

Recall that, as formulated by Pennings, the provision of medical assistance in procreation is acceptable when the child born as a result of the treatment will have a reasonably happy life. There has to be “*a reasonable chance that the future person will have the abilities and possibilities to realize those dimensions and goals that make human lives valuable. All those conditions and defects which obstruct the pursuit of the normal human interests should be considered as harm to the person*”.³⁰ What does ‘normal’ in this sense mean and what is it that makes human lives valuable? And when can we consider something to be reasonable. In other words, in order to determine the meaning of ‘reasonable welfare’ we need to define welfare and we need to define reasonable.

One of the criticisms against Pennings’s account of welfare is that it is too vague. For Pennings this is not a problem: this vagueness is not unique to the reasonable welfare principle, since all standards have grey zones of borderline cases. Furthermore, owing to the vagueness, the standard can be used as a rule-of thumb test, allowing for case-by-case evaluation.³¹ In order to determine what constitutes the normal state of happiness or welfare, we will have “*to rely to a considerable extent on our common sense*”.³² According to Molyneux, many medical ethicists, while writing about welfare, are vague about what they mean by this word.³³ For instance Beauchamp and Childress, in their chapter on beneficence assert that “*Morality requires not only that we treat persons autonomously and refrain from harming them, but also that we contribute to their welfare*”, but they do not offer a definition of welfare.³⁴ But, as Molyneux argues, if welfare is to occupy such a central role in medical ethics, should we not have a clear notion of what it is? Theories of welfare can be either objective or subjective. On an objective account of welfare, an individual’s life can be going well even if he has no

³⁰ Pennings 1999

³¹ Bredenoord 2008

³² Pennings 1999

³³ Molyneux, 2006

³⁴ Beauchamp and Childress, 2009, p.197

positive attitude towards it. On a subjective account welfare is dependent upon our attitudes of favour and disfavour. If the reasonable welfare standard is regarded as an objective account of welfare, we could draw up a list of 'abilities and possibilities' that we think contribute to it.³⁵ Pennings does not provide us with such a list (it is not even clear that his account of welfare is an objective account), but we could imagine that being born with a serious disability with a considerably reduced lifespan would be part of such a list. Would this be sufficient to justify refusal of treatment or should we also take into account how the child could, subjectively, experience its life with such a disability? It is not my purpose here to defend a specific account of welfare, but I think that anyone who wants to defend a welfare standard should do more to define what is meant by it, than simply refer to common sense.

That there is need for a clearer specification of what constitutes wellbeing, is further illustrated by the debate whether to rely on consequentialist arguments only or whether to include deontological arguments as well when assessing the future welfare of the child. Pennings advocates a clear separation of consequentialist and deontological arguments. "*The welfare of the child, i.e. the extent to which its needs are fulfilled, is to a large extent objectively measurable in the sense that it can be determined whether there is a deficiency in the satisfaction of one of the child's needs.*"³⁶ Having the welfare of the child in mind, we should only select on those characteristics that have a *proven* influence on wellbeing and not on ideological or religiously based features. On the other hand, he acknowledges the fact that "*the consequentialist argument is not the sole, let alone the most important relevant moral factor in the evaluation*". However, those with deontological arguments should invoke the possibility of conscientious objection (as long as they remain within the limits of the law). Bolt offers some arguments against the exclusion of deontological arguments for the reasonable welfare principle.³⁷ Pennings refers to 'normal' human interests, but can this do justice to the plurality of opinions about what can make life valuable? And should we not also consider the deontic status of our actions, independent of or in addition to the consequences these actions have? The fact that 'we' consider it an important aspect of what makes life valuable that we can know who our biological parents are, has resulted in policies allowing for children born

³⁵ an example of such a list Nussbaum's capabilities approach

³⁶ Pennings 1999, p. 1149

³⁷ Bolt 2002

after gamete donation to get information on the donor, even though it is not a proven fact that not being able to do so would result in high risk of serious harm.

What about the use of the term reasonable? One of Pennings's opponents argues that we should concentrate on minimal but necessary exclusions when there is a known immediate risk to the welfare of the child.³⁸ Langdrige's use of the word minimal here is confusing. Where Pennings uses the word minimal for those cases where life would be worth less than nothing, Landrigde, I think, uses it to indicate cases that are known to constitute a high risk of serious harm, such as previous convictions for child abuse. "*..., a child born into the care of a convicted child abuser is a clear case where we can (with as much certainty as we can predict any future event) state that there is an immediate and future risk to the child's welfare*". It appears that minimal is used to indicate the absolute lower limit of acceptable procreation (Pennings's minimal threshold) and at the same time is used as some other minimal threshold above which we enter into the grey zone of the reasonable welfare standard. Others have used different ways to describe the distinction between minimal and reasonable welfare. For instance, Jackson distinguishes between a thin interpretation and a thick interpretation of the welfare principle.³⁹ Under the thin version, access could be denied in cases where circumstances would be so bad that non-existence would be preferable, whereas the thick version implies that factors are to be taken into account that would endanger a parents capability of providing adequate care or other risks of harm, that are not so bad as to make the child's life so miserable that non-existence would be preferable.⁴⁰ Steinbock adds to the terminological confusion by introducing the "decent minimum standard" which appears to be rather synonymous to the reasonable welfare standard: "*A decent minimum is reached only if life holds a reasonable promise of containing the things that make human lives good: an ability to experience pleasure, to learn, to have relationships with others.*"⁴¹ So what is reasonable? One thing is certain: all of the above quoted authors agree that the minimum standard as in the absolute or thin version is unacceptable. All agree that some sort of minimal requirement has to be made as to the risk for serious harm, including some sort of appreciation of parental capabilities. The confusion over the wording minimal and reasonable may not be the strongest argument against the

³⁸ Langdrige, 2000

³⁹ Jackson 2002

⁴⁰ *ibid*

⁴¹ Steinbock 2009

reasonable welfare standard, but is illustrative of the indeterminacy of the concept. It can be explained by disagreements as to what would constitute the minimal requirements for reasonable welfare, i.e. the minimum threshold of the reasonable welfare standard. To quote Steinbock again: “This is an issue on which *reasonable* people can disagree”.⁴² That reasonable people disagree about what is reasonable is maybe not so surprising. However, it makes the reasonable welfare standard a very slippery concept.

3.2 The value of empirical data

As said, Pennings advocates a consequentialist interpretation of the reasonable welfare standard. A survey amongst Dutch fertility clinics showed that where empirical evidence is available, this usually becomes the basis on which to decide to treat or not, whereas in those cases where evidence is lacking physicians tend to rely on deliberation with the medical team or intuition.⁴³ The need for systematic studies to establish what actually happens to children born under certain circumstances with regard to their welfare, is generally acknowledged.⁴⁴ According to Pennings one of the major advantages of the welfare of the child as a criterion is that it can be measured, even though ‘it is an extremely difficult task in most circumstances’.⁴⁵ In addition to that, the gathering and use of empirical data also has some problematic issues in itself.

As to the gathering of data, one of these problems is that of selection and publication bias. This may result in prejudiced choice of research focus (we do study effects of growing up with lesbian parents but do we study the effects of growing up in daycare?) and publication only of research that shows interesting and new information.

In studying the effects of new reproductive technologies, the focus is often on short term follow-up of children and long term effects remain largely unknown or time is yet to short to allow the gathering of these data. An additional problem, brought forward by Pennings himself, is that typically in studies on the effects of growing up in homosexual families the heterosexual family functions a control group or ‘the gold standard’.⁴⁶

⁴² *ibid*, emphasis added

⁴³ Bolt et al, 2004

⁴⁴ Glombok, 1998; Bolt 2004

⁴⁵ Pennings 2011

⁴⁶ *ibid*, p.4

As to the way empirical data are put to use: a first criticism put forward by Langdrige has to do with the predictive value of data. The many variables that are at play when we would attempt to predict the welfare of a future child, makes the whole exercise of using a reasonable welfare standard “pointless” and “ridiculous” according to him. This can be countered by arguing that what Pennings implies is not trying to *predict* the welfare, but he only wants to assess abilities and possibilities that might pose a serious risk of influencing the welfare of the future child in a negative way. Nevertheless, sometimes children born under extremely dreadful circumstances may end up living lives that most would consider to be fairly (reasonably?) happy, whereas children born under seemingly advantageous circumstances may end up experiencing their lives to be dreadful.

Secondly, a point brought up by Pennings himself is that some essential factors that have been shown to be of major influence on children’s welfare are not incorporated into an assessment of prospective parents, whereas a focus remains on other factors that have been shown not to be of negative influence. One often quoted study by Golombok showed that aspects of family structure such as genetic relatedness, number of parents and the mother’s sexual orientation, may matter less for children’s psychological adjustment than warm and supportive relationships with their parents, and a positive family environment.⁴⁷ As Pennings argues we should shift our concern from such factors as single parenthood, to factors that are known to influence this ability to provide a positive family environment? For instance, it has been demonstrated that people who have been abused as a child have a much higher risk themselves of abusing their own children.⁴⁸

The above mentioned considerations regarding the gathering and use of empirical data shows that the value of these data may be overestimated and that we should be critical about which data are used to determine the chance for reasonable welfare.

⁴⁷ Golombok 1998

⁴⁸ Not that I think that we should deny treatment to anyone who has experienced childhood abuse, but it would help to anticipate and offer support where needed.

3.3 The aim of the reasonable welfare standard

What do we expect to achieve with the use of a reasonable welfare standard?

The primary goal, I think, is to assure that children born after ART have a reasonable chance of a reasonable happy life. But is it effective in this way, in other words does the use of this standard actually prevent the birth of children who are at risk of suffering serious harm once they are born? Technically, this would be very difficult to determine. What we can look at is how often and for what reasons welfare of the child arguments are actually invoked to refuse treatment. In the Netherlands the policy of assessing access to ART on the basis of the reasonable welfare standard has only been introduced last year, although there is already made longer use of for moral deliberation on cases of prenatal and pre-implantation genetic diagnosis. In the UK a welfare provision was already incorporated in legislation concerning access to ART in 1990, so there has been some more experience over time. In their public consultation "Tomorrow's children" in 2004 the HFEA found that most respondents from staff working in clinics regarded the welfare of the child assessment as an important part of clinical practice, but patients were very rarely turned down for treatment.⁴⁹ There is one report from a Dutch academic fertility centre, where they have been working with a protocol based on the HFEA's code of practice already before the publication of the Dutch protocol. They report that on a yearly basis out of a thousand cases 10 difficult cases are referred for multidisciplinary deliberation and of these two are turned down.⁵⁰ It is difficult to interpret these low numbers both in UK as well as in this report from the Netherlands. It is possible that due to the fact that people have to make a deliberate choice to visit a fertility clinic, many of those who would belong to a risk category do not dare to make this step or refrain from seeking help after consulting their GP. It might however also call into question the practical value of welfare considerations in protecting the interests of children born as a result of assisted reproduction.

⁴⁹ 'Tomorrow's Children', 2004, p.9. *"The reasons to turn patients down were most commonly medical (because the patient had an infectious disease or they were being treated for cancer), psychiatric (because the patient had a mental illness or a drug or alcohol problem) or, occasionally social (because the couple lives apart)."*

⁵⁰ Van Dijk en Laven 2009.

An additional goal of the reasonable welfare standard could be to get a more uniform approach amongst different clinics and physicians towards the assessment of prospective parents. It would be unfair if reasons that would lead to refusal in one clinic would not be problematic in another. The survey amongst Dutch fertility clinics showed that physicians are far from unanimous in their choices whether to treat or not. For example 60 % would deny treatment to a couple when there is the chance of transmitting Huntington and 58 % would refuse treatment in the case of a terminally ill partner.⁵¹ However, the protocol does not provide physicians with uniformity in this way, it is uniform only in a procedural way. Considering the vagueness of the concept and the fact that under the new protocol there is no central committee to which cases are referred, it seems doubtful that this goal will be achieved.

Finally, it could be that the main purpose of incorporating a reasonable welfare standard in the assessment protocol mainly serves as a back-up for physicians. Something they can rely on to legitimize their sometimes very difficult decisions, which they intuitively feel uncomfortable with. In this sense the welfare standard mainly has a symbolic value, by reminding them of the importance to protect children from harm. The main asset of the Dutch protocol as such lies in offering a framework for transparent and careful deliberation that tries to do justice to the tension between the wishes of prospective parents and the professional responsibility of the treating physician. This tension between reproductive freedom and professional responsibility will be the subject of the following paragraph.

3.4 Reproductive freedom versus professional responsibility

An argument that is often used in the debate about acceptable conditions for treatment refusal is that scrutinizing pre-conception decisions of autonomous adults is unjustifiable, because people who can procreate naturally also do not need to subject themselves to such pre-conception assessments. *“In reproductive decision-making of fertile couples, their privacy rights trump any concerns we might have about the risks of harm they present to future children. This makes the welfare of future children to occupy ‘curious middleground’, on the one hand being less important than reproductive freedom of fertile couples but more important than decisional privacy of infertile couples .”*⁵² How can

⁵¹ Bolt 2004

⁵² Jackson 2002

this be justified?

The importance of reproductive freedom is generally acknowledged. This has to do with the primary moral basis of reproductive freedom, which is autonomy.⁵³ The freedom to procreate or not is integral to a person's sense of being the author of his or her own life plan. Reproductive freedom most commonly focuses on the right not to procreate if one wishes. Thus, focus has typically been on access to the means to avoid procreation—contraception and abortion. But reproductive freedom also encompasses a right to procreate, or at least to attempt to procreate, if one wishes. That is why sterilization of persons deemed unfit to procreate like mentally retarded persons is considered to be a violation of the right to reproductive freedom.⁵⁴ Some individuals can only exercise their right to procreate with the use of ART. Does the right to reproductive freedom also encompass a claim of access to ART? This is not generally accepted. The right to reproductive freedom is considered to be a negative right; it does not require that others furnish or fund ART for those who need it, but only that others, including the state, do not interfere with an individual's use of ART if she can find someone willing to provide it.⁵⁵ However, in a publicly funded health care system such as in the Netherlands they might still claim treatment based on the right to equal access to health care. So refusing access to ART requires additional justification. There are two arguments on offer. First, refusing ART is less intrusive than intruding on fertile people procreative actions. This argument explains why we should be reluctant to intrude in cases of natural procreation, but does not explain why we should intrude in cases of ART.

The second argument is that in ART there is a physician involved. The dual responsibility of the physician that I referred to in the introduction, requires him to take into account the welfare of the future child. This leads us to the question of moral justification of this obligation that physicians supposedly have towards future children. This question confronts us with the non-identity problem, which will be the subject of the next section.

⁵³ Brock 2005; the two other moral basics for reproductive freedom are equality and individual wellbeing.

⁵⁴ *ibid*

⁵⁵ Brock 2005, Bolt 2004: p. 47

3.5 The non-identity problem

Many of us will feel that we have obligations with respect to the welfare of future generations. It explains why we worry about disposal of nuclear waste, the depletion of energy sources and global warming, even though these future generations do not exist at the moment of our actions that they may suffer the consequences from.

Many will also believe that it is wrong to bring a child into existence that is expected to have an awful life, despite the fact that this child does not yet exist at the time of our procreative act or choice. It is this intuitive belief that is the main reason for our appeal to a principle of reasonable welfare when refusal of access to ART is deemed to be wise.

Intuitive moral beliefs can be challenged and may have to be revised when they are incoherent with moral theory and vice versa. The non-identity problem poses such a challenge for considerations regarding the welfare of a child that will be born as the result of ART. In the following section I will address the non-identity problem, how it makes the use of a welfare standard for access to ART problematic and review possible solutions to overcome or bypass this problem.

The non-identity problem refers to the fact that some of our choices, which affect the welfare of people, also affect their identity. One of Parfit's examples to explain what the non-identity problem entails, is the case of the 14-year-old-girl:

*"This girl chooses to have a child. Because she is so young, she gives her child a bad start in life. Though this will have bad effects throughout the child's life, his life will, predictably, be worth living. If this girl had waited for several years, she would have had a different child, to whom she would have given a better start in life."*⁵⁶

Those of us who consider that having a child at age 14 is morally wrong (assuming the girl has been counselled about the possible consequences of her actions for the child but still decides to do it), do so because they think the child is harmed by her decision, it will have a bad start in life. Believing this means accepting a person-affecting intuition, because "what is bad must be bad for someone"⁵⁷ (Parfit p.363). Under a person-affecting view, harm implies that we need to be able to compare two conditions: the

⁵⁶ Ibid, p.

⁵⁷ Parfit p.363

current condition, and the condition that would have been the case if the harmful act had not occurred, the 'unaffected' condition. If the current condition is not worse compared to the unaffected condition, this person is not harmed and the act cannot be morally wrong. However, the "wrong" act is (in this case as it is with all procreative acts, assisted or not) the very act that has brought the child into existence. Considering that the child overall has a life worth living, it cannot be said to be harmed by this act. In other words, in the case of procreation the unaffected situation is the pre-conception state that can be considered not to be a state at all (den Hartogh). If the girl had decided to postpone her plan of having a child, any child that would be born at a later date would always be a different child i.e. a non-identical child compared to the one she would have had at the precise moment at the age of 14 at which she decides to get pregnant. Hence the term 'non-identity problem'.

Maybe you are not convinced that having a child at age 14 is wrong, because you may not know for sure beforehand that the child will indeed have a bad start in life. Then consider the case of the woman who wants to get pregnant but is currently suffering from a disease that, should she get pregnant, will with absolute certainty result in the birth of a seriously handicapped child. However, if she waits two months the disease will have disappeared and there is no longer the risk of a handicapped child (at least not from this cause). If the woman does not wait two months before she gets pregnant, we will most certainly consider her to have acted in a morally bad way because her child will suffer from a severe disability. However, as the nonidentity problem shows, this child cannot be said to be harmed by the woman's decision because it would otherwise not have existed.

What does this mean for the assessment of right and wrong in cases of assisted reproduction? In ART we are also dealing with a child that does not yet exist. Not assisting in creating this child is not for the benefit of this child (it cannot be benefitted by non-existence) nor can the child be harmed by being brought into existence (when its life will be overall worth living). Accepting the non-identity problem means that only two types of action can be harmful to the child: either bringing into existence a child that has a truly awful life (a life not worth living), or bringing into existence a child with a life

worth living while we had the alternative of bringing *that same child* into an existence that was substantially better.⁵⁸

Since it will be extremely difficult for many to give up on the intuitive belief that assisting in the creation of a child that will have a miserable life is wrong, we need some sort of solution for the non-identity problem. In other words, we want to be able to conclude that the act of assisting in procreation in certain cases is wrong, even though we can not say that the child is harmed if we do assist in bringing this child into the world. Many authors, including Parfit himself, have considered ways to overcome the non-identity problem. In the following section some of these options will be discussed.

How to deal with the non-identity problem

There are many different approaches to the non-identity problem. Roughly they can be categorized as follows: 1. adopt an impersonal approach thus denying the problem of non-identity 2. figure out some way to retain the person affecting view of harm but still avoid the non-identity problem, 3. Adopt a strict person-affecting view and accept the implications of the non-identity problem.

Ad 1. Impersonalism.

Impersonalism denies the person-affecting nature of value, but it addresses value to the world in general.⁵⁹ As opposed to the person affecting view, that evaluates the outcome based on how it affects the welfare of others, the impersonal view focuses on the quantity of welfare that an outcome contains. If on a person-affecting account we would say that something is wrong because it makes a person worse off, when we say that something is impersonally bad it is so because it makes the world worse without being bad for any particular person.

Den Hartogh uses an interesting analogy to explain how impersonal considerations can explain why physicians sometimes want to deny access to assisted procreation, even though they cannot say that they do so 'in the interest of the child'.⁶⁰ He compares having a child to the project of writing a novel, which goes as follows: Suppose you plan to write a novel, but when you start writing you realize that it is not going to work out the way you had initially hoped for. So you might decide to stop. The

⁵⁸ Roberts and Wasserman 2009

⁵⁹ Heyd 2009, p.7

⁶⁰ Den Hartogh 2006

reason to give up on your project of writing a novel is not that if you were to go ahead and wrote the novel anyway, this would be harmful to anyone; it is a project that hasn't turned out the way you hoped before you began. Conceiving a child is such a project: once you realize that the child will face a life with great difficulties, you have reasons not to go ahead with the project, even if proceeding would not logically imply that the child that will be born under the event that you were to proceed can be considered to be harmed. Comparing writing a novel to assisting in the procreation of a child is motivated by the fact that both are instrumental, a child is not created for the benefit of the child itself. A physician also is taking part in the project of medical science and it is contrary to this project to assist in the creation of a life that will have severely diminished welfare. This line of reasoning shows how impersonal considerations can lead us to avoid the non-identity problem and allows us to say that bringing a seriously handicapped or disabled child into the world is to cause avoidable suffering, falling short of the professional responsibility of the physician. The act is wrong in virtue of impersonal effects without being worse for any person who does or will exist.⁶¹ However, it is still very much a common sense like line of reasoning. In order to develop a more complete theoretical account of what our duties are to future children, several accounts have been proposed that adopt an impersonal approach in one way or another in order to avoid the non-identity problem.

On one version of such a view, the total view, as formulated by Parfit, other things being equal, the best outcome is the one in which there would be the greatest quantity of whatever makes life worth living. It is not important who is made better off by some beneficent act as long as it creates more happiness in the world than any alternative act. From this perspective '*a world of a million happy people is better than a world with no people at all. And it is also better than a world with half a million equally happy people, even if these are completely different people.*'⁶² This is what Parfit has called the repugnant conclusion.⁶³ In other words, if what we ought to do is to increase wellbeing in general, this implies an unconstrained obligation to procreate. Bringing a child into the world that has a miserable life but a life that is still to be considered worth living,

⁶¹ Roberts and Wasserman 2009, p.xxi

⁶² Heyd 2009, p.6

⁶³ Parfit, p. 388 Parfit's formulation of the repugnant conclusion literally goes: "For any possible population of at least ten billion people, all with a very high quality of life, there must be some much larger imaginable population whose existence, if other things are equal, would be better, even though its members have lives that are barely worth living."

will add to overall wellbeing compared to not bringing this child into existence. Thus this option would be the preferable one. This is something most people are not willing to accept. Proponents of a total view may offer arguments against the inference that adopting this view leads to the repugnant conclusion, for instance by arguing that expansion of the population may not be the only way to increase the total amount of what makes the world better. If there are other ways of increasing overall welfare that are more efficient like making existing people happier instead of making happy people, the total view would not require an unconstrained obligation to procreate but might even disallow creating more people! ⁶⁴

As an alternative to a total view, we can adopt an impersonal average view, which implies that the best outcome is the one in which people's lives go best, on average. This would avoid the implication that we have an unconstrained obligation to procreate, but has other implications that can be considered to be problematic. For instance, we would have to accept that bringing beings into existence that will, on average, lower the amount of whatever makes the world better, is wrong, even if these beings would have lives well worth living. ⁶⁵

Another approach to avoid both non-identity and repugnant conclusion is to restrict the obligation to create additional wellbeing to cases where the future child that is expected to have diminished welfare by another single, non-identical child, with an expected better welfare. For this approach Parfit formulated his principle Q or same number quality claim: *'If in either of two possible outcomes the same number of people would ever live, it would be worse if those who live are worse off, or have a lower quality of life, than those who would have lived'*.⁶⁶ This approach is also referred to as same-number substitution or avoidance by substitution and is a utilitarian principle that seeks to minimize overall suffering, but requires the numbers of people that will exist to remain the same. ⁶⁷ Such a solution can solve the case of the woman who has to wait two months to be cured from a disease in order to conceive a child that will not be handicapped. It allows for accepting that the child when conceived before the disease has cleared up is not harmed, but can still justify postponing on the basis of the duty to minimize overall suffering. However, in many cases of ART it is simply not possible to

⁶⁴ Visak, p.199

⁶⁵ Parfit's mere addition paradox

⁶⁶ *ibid*, p. 360

⁶⁷ Robertson 2004

substitute a child with an expected reduced level of welfare for a non-identical child with a reasonable level of welfare. As Robertson formulates it: *“to substitute a healthy child would require that the parents give up having a genetically related child and accept childlessness, adoption or use of a gamete donor. Or they would have to incur the physical burdens and financial costs of more IVF cycles. Or substitution may require invasive prenatal diagnostic procedures and destruction of embryos and fetuses, which many people oppose, even on the assumption that an unaffected child would then be born instead.”* ⁶⁸ The need to keep the numbers the same and not unreasonably burden parents in making substitutions thus constrains the impact of this solution. It cannot solve the so called ‘different number choices’, i.e. those cases where, if we decide not to treat, there will be no child at all and thus the substitution principle cannot be applied.

⁶⁹

Recognizing this problem, Parfit tried in his book to develop his principle ‘Q’ into a broader “theory X”, but failed, on his own account, to come up with a sufficient answer and concluded with expressing the hope that some future solution would be found. In search for such a solution, attempts have been made to incorporate both person-affecting and impersonal elements into one theory, either by adopting an aggregative or a restricted form. On the aggregative form the impersonal increase or decrease of what makes the world better has to be balanced against any possible person-affecting reasons that work the opposite way. So, bringing a disabled child into the world that has a life that is overall worth living might be good for impersonal reasons but bad for person-affecting reasons like the implications the existence of this child will have for the parents, siblings and other third persons whose wellbeing may be affected in a negative way by the birth of the child. What ought to be done depends on how these reasons can be balanced against on another. Against this approach it has been objected that it would lead us to have to deny ‘the asymmetry’ within our moral reasoning whether or not to bring a child into existence: on the one hand the expectation that a child’s life will be so miserable that it will not be worth living provides us with a reason not (to assist) to bring this child into existence, on the other hand the expectation that the child’s life will be well worth living (‘reasonable happy’) does not provide us with a reason to bring the

⁶⁸ *ibid*

⁶⁹ Different number choices also includes choices where one action would result in more children than any alternative action

child into existence.⁷⁰ For those who want to hold on to ‘the asymmetry’ incorporating impersonal elements in an aggregative way is problematic.

Buchanan et al. propose a restricted form in which person-affecting and impersonal evaluations are incorporated into one theory. For the evaluation of the morality of actions that affect our children post-conceptionally, they adopt in general a person affecting approach, which is represented by a principle M: *‘Those individuals responsible for a child’s, or other dependent person’s, welfare are morally required not to let it suffer a serious harm or disability or a serious loss of happiness or good, that they could have prevented without imposing substantial burdens or costs or loss of benefits, on themselves or others.’*⁷¹ However, in cases where moral judgement is to be made before conception we cannot appeal to M but should instead appeal to a principle N, which is a formulation of the avoidance by substitution principle.⁷² Again, such a solution is only applicable in same number choices and is therefore of limited use. This approach and other attempts to incorporate both person and non-person affecting considerations are criticised by Heyd for being ad hoc at most, because it does not offer a principled way of relating these two principles. “ *Its ad hoc nature is manifest in the author’s claim that the impersonalist principle is to be introduced only when the suffering or the “defect” of the child is “serious” But non-identity is not a matter of the degree of harm or pain but a conceptual constraint regarding the conditions for making any moral judgement .*⁷³

If we now look again at the explanation offered by Den Hartogh: bringing a seriously handicapped child into the world does not harm that child but is wrong because it is contrary to the professional responsibility of the physician to prevent unnecessary suffering. How does this fit within the proposed solutions on offer in this paragraph? It can be seen as part of a double principle solution as offered by Buchanan (principle N representing the professional responsibility in pre-conception cases). We might on the other hand adopt a negative account of an impersonal approach (i.e. without trying to incorporate person-affecting elements). It is negative in the sense that it recognizes a duty to prevent unnecessary suffering, without at the same time implying a duty to increase wellbeing (which would imply the repugnant conclusion of an unconstrained obligation to procreate). Such a negative obligation is formulated by

⁷⁰ McMahan 2009

⁷¹ Buchanan et al 2000, p.226

⁷² *ibid*, p.249

⁷³ Heyd 2009

Harris as follows: “ ... a strong moral obligation to prevent preventable harm and suffering and that this obligation applies equally to curing disease and injury and to preventing the avoidable creation of people who will have disease or injury”.⁷⁴ Considering that almost everyone will, at some point in his life, be confronted with disease or suffering, we would then have to explain why it would still be permissible in many cases to assist in bringing children into this world if its not for positive impersonal reasons, i.c. that bringing children into the world is a means to make the world better.

Summarizing the above, adopting an impersonalist perspective can avoid the non-identity problem but has implications, like the repugnant conclusion, that we subsequently have to avoid. Some cases, the so-called same number cases, can be solved by adopting a principle of ‘avoidance by substitution’, but there remain unresolved issues in different number choices. Attempts to incorporate person-affecting and impersonalist perspectives in one theory have failed (Parfit) or can be criticised for offering only an ad hoc or limited solution.

Although impersonalism seems to offer at least part of a solution, this will nevertheless not be acceptable for those who want to stick to a strictly person-affecting view. Can the non-identity problem be solved under a person-affecting approach? This will be the subject of the following paragraph.

Ad.2 Avoid the non-identity problem under a person-affecting approach.

Recall that under a person-affecting view we judge our acts to be right or wrong depending on the way it makes those whom our acts affect better or worse off.

One obvious way to judge procreative assistance in some cases is to look, not at how the act affects the future child, but how it affects others, currently existing beings. For instance, as suggested by Robertson we might consider not focusing directly on the welfare of the child, but focus on the burdens and demands that the birth of a child with a highly diminished welfare imposes on others. If harms to third parties (parents, siblings, society) are sufficiently great, limiting access to ART results from the duty not to harm others.⁷⁵ However, he immediately points out the problem with this approach. Suppose a couple decides to intentionally conceive a child (with the help of ART) that is severely disabled (but not as to make its life not worth living). Further, this couple has

⁷⁴ J. Harris 1998

⁷⁵ Robertson 2004

clearly expressed the intention to provide the child with all the love and care that it needs *and* they are fully aware of and accept the consequences of having to take care of a severely disabled child *and* they will not depend on any support from societal resources, there is no harm done to third parties and we no longer have a ground to refuse access to ART.

Another approach offered by Robertson is to shift our attention from how our acts affect resulting children or third persons, and focus instead on the persons who willingly undertake to procreate despite the risk of having offspring with a lower quality of life and ask whether they are exercising procreative rights in making such a choice. If not, they have no special claim to engage in that activity nor can they claim a right to assistance. On this account, parents who are willing to take risks or bring children into this world without a reasonable chance of having reasonable welfare (a greatly reduced quality of life) are not pursuing reproductive needs as commonly valued and understood and therefore no longer deserve special protection based on reproductive freedom. According to Robertson however, this only applies in cases where parents are not willing to rear and take care of their children, “whatever their condition”, thus adopting a very liberal interpretation that would not fit well with the concept of the reasonable welfare principle.

Solberg also tries to defend a person-affecting view without having to show that potential people can be harmed.⁷⁶ She argues to reject a ‘welfare-of-the-child’ based approach for reproductive ethics in favor of an approach that is based on the desired goal of ART. Her argument involves the idea of futile care. A treatment can be considered to be futile if it has an extremely low chance of achieving the desired goal. She formulates the goal of ART as follows: “*the goal is to produce parents in the social meaning of the word – by way of biological intervention – and in that sense, building functional families is the primary goal of the treatment*”. In other words, the goal of ART is not just about parenthood in the biological sense. There is more to it and this we may assume because reproduction by ART is always the result of a deliberate and intentional choice and this intentional choice implies or should imply an intention and willingness to function as a parent. If there is every reason to suspect that the prospective parent(s) will not be able to become a parent in the functional meaning of the word, the treatment can be considered to be futile. The futility of the treatment lies in the fact that it is not in

⁷⁶ Solberg 2009

the interest of the prospective parents to procreate. Apart from the fact that this sounds overly paternalistic, we still cannot account for the cases where the parents have every intention and capability to function as parents, but we still wouldn't want to assist (eg. in the case of bringing into existence a child with a severe disability or a genetically enhanced child). Solberg, recognizing this problem, further suggest a second version of futility, one that relates to public interest, explained as follows: "*All of us – that means generations living here and now – have an interest in what kind of future children are created since we are going to interact with them. We have an interest in avoiding Huxley's "Brave New World", because we value free and autonomous beings. Reproduction, for us, means reproducing such fundamental ideas in a partly different other. If the "production" of a certain type of offspring involves the blocking of the dialogical relation between a parent and child, the parental project is futile*". I doubt that these are the kind of considerations that are helpful in the daily practice of assisted reproduction (or helpful at all). It would be at least quite difficult to 'sell' it to a couple that visits the fertility clinic. An approach like this may at most be useful for general policy, when decisions have to be made on the introduction of new technologies and as Solberg herself indicates by referring to Brave New World on questions about cloning or enhancement.

Another way to handle the non-identity problem is to show that even if an act does not make things worse for someone, it can still be bad and therefore wrong. In this category we find a rights based solution and the use of a non-comparative account of harm. The rights based approach argues that children have a 'birthright' to a life above a certain threshold. If it cannot be reasonably assured that they will at least have a decent minimum welfare people have a right not to be brought into existence.⁷⁷ This approach can best be explained by another famous example, that of the slave child. A couple enter into a contract that obliges them to have a child, which they then will sell as a slave. Had the couple not entered into the contract the child would not have existed and thus not made worse off. When we accept that everyone has a right not to be born a slave, what the couple does when they do bring a child into the world, is violating this right: it is bad for the child (and therefore wrong), but the child cannot be said to be made worse off, since we cannot compare existence with pre-existence. There are several objections to this approach, of which I will only mention one. If the child has rights, the parents have too. Whose rights trumps the other's if they cannot both be respected?

⁷⁷ Steinbock 2009, p.166

The other option mentioned above is to use a non-comparative account of harm. The non-identity problem relies on the argument that if an act does not make a (future) person worse off this person cannot be considered to be harmed. This is a comparative account of harm. On a non-comparative account of harm an agent harms a person, when the agent causes the person to be in a bad state, such as “pain, early death, bodily damage, and deformation”.⁷⁸ (Harman). Bad states are bad in themselves, and not because they are worse than the state the person would otherwise have been in. According to Harman’s view, when an act is harmful (as in the non-comparative account), the fact that this act at the same time also benefits this person, is not sufficient to justify the harm. The child that is brought into existence may not be harmed as in ‘made worse off’ but it does cause the child to be in a bad state.

However, there is at least one objection: can this sufficiently explain the wrongness of the procreative act in terms of the effects it has on the child? If the life of this child, though difficult or painful, would still be a life worth living, it is possible that this child would consider the difficulties it is confronted with “*a perfectly acceptable price to pay for a life he could not have without it*”.⁷⁹

In this section we have looked at solutions that depart from a person-affecting perspective on harm but try to avoid the non-identity problem in one way or another, but it seems that each of the discussed options has to face objections. Although this overview is far from complete –whole books have been written about this subject – this only goes to show that so far there is not really a fully satisfying answer to the non-identity problem. Does this mean we have no other choice than to accept the implications of the non-identity problem?

Ad 3. Accept all implications of the non-identity problem

So far we have discussed options that may allow us to consider some cases of (assisted) reproduction wrong, despite the non-identity problem, either by adopting impersonalism or by retaining the person- affecting approach. As we have seen the many attempts, although sometimes plausible or at least possible to solve the problem in part of the cases, often are not capable to fully overcome the non-identity problem or, if they do, run into some very counter-intuitive implications.

⁷⁸ Harman 2009

⁷⁹ Wasserman 2005

The hope, expressed by Parfit, that some theory X might be developed, is misguided because there is *'nothing that we don't know "yet" about the matter'* that would help us to figure out the conflict between non-person affecting theories of value, that lead to absurd conclusions like the obligation of unconstrained procreation and the person affecting approach which also, due to the non-identity problem, results in conclusions we are not willing to accept.⁸⁰

Thus, if all else fails, we might conclude that we just cannot avoid the non-identity problem, without letting go of a person-affecting view of harm, and must face the consequences, like not being able to judge some procreative acts in which the child to be born will suffer. According to Heyd, who, in his own words, is an advocate of such a strict person-affecting view, this does not necessarily mean that we have to accept these counterintuitive consequences. Alternatively, he suggests a sceptical view as to the possibility of finding a normative justification for procreative prohibitions (such as the refusal to offer ART in some cases). *"This sceptical attitude is compatible with leaving the actual moral and political choice to be guided by intuitions and public perceptions even when these are confused and inconsistent. For anyone who is not a stringent impersonalist and who is convinced by the arguments against a diluted or comprised version of the person-affecting view, the strict or narrow person-affecting analysis seems to be the lesser theoretical evil in being both consistent and doing justice to some of our fundamental intuitions."*

With these remarks this chapter is concluded. Next, in the final chapter, I will elaborate on the possible implications resulting from the issues discussed in this chapter for the ethical evaluation of assisted reproduction when there are legitimate concerns for the welfare of the future child.

⁸⁰ Heyd 2009, p. 17

4 General Discussion

In his essay on the moral status of children, Freeman quotes John Stuart Mill, famous for his harm principle, who already in his days recognized that “...to bring a child into existence without a fair prospect of being able, not only to provide food for its body, but instruction and training for its mind, is a moral crime, both against the unfortunate offspring and against society”.⁸¹ In those days the state or society could only interfere after the child was born, whereas nowadays, in cases where procreation is only possible with the help of ART, we can intervene. Not only that, it is a commonly held belief that we (in the role of the physician offering ART) *should* do so in cases where we have reasons to fear for the welfare of the child that will be born as a result of our treatment. And when we do, we should let our decisions be guided by the reasonable welfare standard. This, at least, is the dominant view currently advocated by the Dutch and other European professional organisations.

In the previous chapter I have examined issues that might make the use of such a welfare standard problematic. I will first address the issue of the non-identity problem. Within the scope of this thesis I have not strived to offer a complete account of all possible and proposed solutions to the non-identity problem. Even with this limitation, I believe that the discussion on the non-identity problem shows that, both on an impersonal account and a person-affecting account or a combined theoretical account it is difficult to come up with a theoretical explanation of the responsibility we have towards future children that will be born with our help without having to accept all sorts of difficult consequences. Accepting that there is no theoretical justification for such a responsibility leaves us with two options.

The first option is to conclude that there is no responsibility to future children and reject the reasonable welfare standard in favour of a minimum welfare standard or maybe not even that. This doesn't mean a physician can never refuse treatment to anyone. As discussed a right to treatment cannot be claimed, unless it can be shown that in similar cases treatment has been provided to others and as long as the physician does not violate anti-discriminatory legislation. But such a refusal would be difficult to defend from a welfare of the child perspective.

⁸¹ Freeman 1997.

The second option is to adopt the sceptical attitude suggested by Heyd as mentioned in the last paragraph of the previous chapter. Leaving actual moral choice to be guided by intuitions and public perceptions, would allow us to retain the reasonable welfare standard at the price of being accused of being confused and inconsistent.

Could it be that a more sophisticated way of adopting this second option would be to accept some form of common morality theory, the most well-known of course being the principlist approach to biomedical ethics proposed by Beauchamp and Childress?⁸²

The way Beauchamp and Childress view the common morality is that it is a product of human experience and history and a universally shared product. It is the set of norms shared by all persons committed to morality. This common or universal morality is not relative to cultures or individuals, although moral pluralism can be present in particular moralities. Professional moralities are one form of particular morality. In medicine, professional morality specifies general norms for the institutions and practices of medicine. Special roles and relationships in medicine require rules that other professions may not need. Members of professions often informally adhere to widely accepted moral guidelines, but formal codification of and instruction in professional morality has increased in recent years. The protocol concerning possible moral contraindications for assisted reproduction could be considered to be such a formal codification. With their four principle approach Beauchamp and Childress do not claim to present a complete comprehensive ethical theory. The four principles (respect for autonomy, justice, beneficence and nonmaleficance) are part of the common morality and basic for biomedical ethics. They function as general guidelines for the formulation of more specific rules. Their choice of these 4 principles is based on their evaluation of “considered moral judgements and the way moral beliefs cohere”.⁸³ The prima facie obligations that can be derived from these principles may conflict and the actual obligation is determined by examining the respective weight of the competing prima facie obligations. A process of specification of the principle followed by weighing and balancing of competing moral norms will eventually determine what ought to be done. The reasonable welfare principle that tells the physician that he should not provide ART unless the resulting child will have a reasonable chance of having a reasonable happy

⁸² Beauchamp and Childress, 2009

⁸³ Ibid, p.13

life can be viewed as a specification of the principle of beneficence and will have to be balanced and weighed against the competing norms such as reproductive autonomy.

A major criticism against the principlist approach is that it does not provide us with a univocally correct way to specify and balance norms in particular moral contexts. Their account will not necessarily allow us to choose between competing lines of specification and balancing that share the same ultimate anchor in the common morality (Arras).⁸⁴As we know from the euthanasia debate: the moral principle ‘do not kill’ (a specifying rule of the principle of nonmaleficence) can plausibly be further specified in both permissive and restrictive directions. Similarly, opponents and proponents of a reasonable welfare standard can argue for or against it following different lines of specification, ascribing different weights to either one of the principles.

It seems like a missed opportunity that Beauchamp and Childress nowhere in their latest edition of their “Principles of Biomedical Ethics” address the issue of professional responsibility with regard to future children in the context of assisted reproduction. Given the fact that they construe harm ‘exclusively in (...) non-normative sense of thwarting, defeating, or setting back some party’s interests’⁸⁵, it would be difficult to defend refusal of ART as following from either their principle of nonmaleficance (not causing harm) or beneficence (preventing harm), without falling into the trap of the non-identity problem. In adopting a method of wide reflective equilibrium into the justification of their method, which requires them to strive for coherence between considered moral beliefs, ethical principles and background social, psychological and philosophical theories, the non-identity problem might further complicate matters here. However I guess they would not be troubled by the fact that ‘the non-identity problem’ poses a theoretical dispute among diverse ethical theories. As they see it, *“Competition exists among the various normative theories, and competing conceptions exist about how such theories relate to biomedical practice. Nonetheless, we stand to learn from all of these theories. Where one theory is weak in accounting for some part of the moral life, another is strong. Although every general theory clashes at some point of view with our considered moral convictions, each articulates some point of view that we should be reluctant to relinquish. This approach to theories allows us to focus on acceptable features in theories without having to choose one theory to the exclusion of the*

⁸⁴ Arras 2009

⁸⁵ Beauchamp and Childress 2009, p.152

others."⁸⁶ Furthermore, they emphasize that it would be unreasonable to expect a perfect equilibrium and that particular moralities are 'continuous works in progress'.⁸⁷

For now I believe, we will have to contend that the matter of non-identity remains unsolved and poses a serious challenge to the development of moral theory. Whichever of the two options anyone personally might prefer, it seems likely that given the consensus at a national as well as European level concerning our obligations to children born as the result of ART, physicians will opt for the more pragmatically attractive approach of the second option (with all its flaws) as opposed to the more theoretically attractive approach of the first option.

In that case we now have to address the issues that relate to the indeterminacy of the concept of reasonable welfare. This indeterminacy stems from the conceptual difficulty of defining what constitutes reasonable welfare and the limitations of using empirical data to support such a concept and the question if the standard will be effective in achieving the desired goal.

As discussed earlier, the reason to prefer the reasonable welfare standard is that the two other options, the minimal and maximum standards provide us on the one hand with no reason to refuse ART unless the expected life of the child will be not worth living or on the other hand with always a reason to refuse ART because circumstances will never be ideal.

In the previous chapter I have concluded that the reasonable welfare standard is a slippery concept. Whereas proponents of this standard consider its vagueness as an asset, I consider it to be an argument against the usefulness of appealing to such a standard. Given the fact that reasonable people (these I take to include the prospective parents) can disagree on what constitutes reasonable welfare (or what constitutes a high risk of serious harm) how are we to make a conclusive assessment? Let's take a difficult case, Huntington's disease, as example. The Dutch survey showed that 60 % of physician would refuse treatment in such a case.⁸⁸ This is a good example because the reasons to refuse treatment were mainly based on considerations for the welfare of the future child.⁸⁹ The conditions of the disease are well known and there is no cure or

⁸⁶ Ibid, p.363

⁸⁷ ibid, p. 383.

⁸⁸ Bolt 2004

⁸⁹ and not, as for instance in the case of posthumous reproduction, related to considerations for the disruption of the mourning process and welfare of the partner.

treatment to alleviate the symptoms (yet). The couple has thought it over very carefully but does not wish to perform PGD or use a gamete donor. The risk of transmitting the disease is 50 %. Now consider if applying the reasonable welfare standard would make any difference for the outcome the decisions? Would it, in other words, be likely that we can now eliminate any disagreement and conclusively decide for or, maybe more likely, against treatment in cases where there is the possibility of transmitting this disease? I think not. It is much more likely that there will still be those physicians who believe that knowingly and intentionally bringing a child into the world that might be burdened by this terrible disease is wrong and those who may feel that the life to be lived by this child can be so worthwhile despite this burden that it would not be a reason not to bring such a child into existence. Against this line of reasoning it can be objected that complete agreement is not the objective. This may be true but we would at least want such an amount of agreement that we can make a conclusive decision. I suspect that the reasonable welfare standard is not action guiding in such a way that we would want a moral rule to function and that its value within the protocol is for a great deal symbolic. This suspicion is however not grounded on empirical data and I do think it would be interesting to investigate the practical value of the standard by examining the cases that are taken into deliberation, compare cases of different clinics and evaluate the reasoning that is applied to justify a decision. A lot may also be learned from the experience with this standard in other fields like the assessment of cases for PGD.

With regard to the procedure to assess and evaluate cases, other questions can be raised. One of the assets of the Dutch guideline is that it offers a format for a transparent decision procedure to be used by all clinics. However, it expects physicians only to marginally examine possible factors that might pose a risk for the future child and hardly offers any guidance to what such an examination should include. This increases the risk for arbitrariness in the assessment of prospective parents. Furthermore, if we consider the welfare of the child to be important, why should we be so reluctant with our inquiries? On the other hand, knowing that we should be careful in our appreciation of the outcome of empirical research on welfare of the child, it might be quite complicated to draw up a list with questions to be asked in the anamnesis without unnecessarily invading the privacy of the patients. As to the assessment of cases in a multidisciplinary setting: what if out of ten members of a multidisciplinary committee six are against and four have no problem with providing treatment, do we call a vote?

Would it not be reasonable to admit that if at least some of the committee's members disagree that this would lead us to decide that there is insufficient ground to refuse treatment? Furthermore, it is also not clear what the status is of a negative advice. Can the treating physician still go ahead if he disagrees with the negative advice? These are all open questions that I believe need to be addressed.

To conclude, let's reconsider the case of Lucy, the woman with an inheritable predisposition for blindness, that I presented in the introduction. After having delved into the matter of reasonable welfare as an evaluation standard for this thesis, I have to admit that I still do not really know what would be the right decision. With my focus on problematic issues of the reasonable welfare standard as explored in this thesis, I do however not want to disregard the difficulty of decisions that sometimes have to be made and the difficult spot physicians can find themselves in when they fear for the welfare of a child that will be born as the result of their actions. These feelings of responsibility, even if they cannot be grounded in a theoretically satisfying way, need to be addressed and as such the current guideline is an important step forward. On the other hand, we owe it to the prospective parents (and their children?) who are depending on the help of the physician to remain critical and keep working towards improvements wherever possible.

Summary

This thesis explores problematic issues in the ethical evaluation of providing access to assisted reproductive technologies. Current practice advocates the use of a reasonable welfare standard that states that refusing treatment is justified when the future child will not have a reasonable chance for a reasonably happy life. Problematic issues relate to the indeterminacy of the concept and the difficulty of formulating a theoretical justification for the physician's responsibility for the welfare of the child that will be born as a result of assisted reproduction because of the non-identity problem. The absence of a satisfying theoretical explanation for the professional responsibility for the future child, as a result of the non-identity problem, forces us to either reject the welfare standard or opt for a more sceptical approach or a pragmatic solution offered by a principlist approach, that might allow the use of a welfare standard. Due to the indeterminacy of the reasonable welfare principle it is suggested that its value for the assessment of cases may be limited, a matter that would have to be investigated further.

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