

und gezielter PID klar zweckorientierten Erzeugung desjenigen Kindes, das für ihr krankes Kind Heilung bringen könnte. Aus dieser individuellen Notlage heraus ist das Handeln der Eltern verständlich und der Vorwurf der Instrumentalisierung wird relativ. Kann man es Eltern verdenken, dass sie diese allerletzte Möglichkeit in Anspruch nehmen, um ihrem kranken Kind zu helfen?

Die grundsätzliche Ablehnung jeglicher Selektion aufgrund bestimmter Merkmale, sei es im positiven oder negativen Kontext, kann im individuellen Fall oft nicht aufrecht erhalten werden, da die Gründe, die zu einer Selektionsmassnahme führen, wie im Falle von Elodie, schwerer wiegen als die grundsätzlichen Gründe dagegen.

Dennoch ist es klar, dass im grösseren gesellschaftlichen Zusammenhang der Automatismus einer Diagnostik und Selektion, wie er bereits bei der pränatalen Diagnostik weitgehend stattfindet, vermieden werden muss.

Dazu braucht es einerseits den entsprechenden gesetzlichen Rahmen, der Missbräuche verhindern sollte und andererseits die ausführliche Information und eingehende Beratung, die im Idealfall zu einer Bewusstwerdung führt um welche Werte es eigentlich geht. Im besten Falle könnte so jeder Mensch befähigt werden in betreffenden Situationen entsprechend den eigenen Wertvorstellungen eine Entscheidung pro oder kontra einer Diagnostik mit allen Konsequenzen fällen zu können.

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Dekanting Preimplantation Genetic Diagnosis and the saviour child: a personal memoir

_Viewpoint

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Being both an academic bioethicist and a member of a national ethics body (in my case, the Swiss Bioethics Advisory Commission – NEK-CNE – from 2001 to 2007) is not always easy. The rules of the academic world favour independent thinking, speculative boldness, and examining all arguments with an open eye no matter how preposterous or politically incorrect they may appear at first sight. In «public bioethics» however, possible discourses are heavily constrained by extraneous considerations. For one thing, the state of current law and the limits of realistic changes carry much weight. As the saying goes, *la politique est l'art du possible*, and what counts as possible in politics bears little relation to what counts as plausible, or at least worth discussing, in the philosophy seminar. More troublingly perhaps, arguments that cut no ice with many philosophers, or at least are considered massively controversial, are sometimes treated as sacred mantras in public bioethics. Such is the concept of «human dignity». Someone only needs to assert, in the appropriately dour tone, that a particular biomedical practice is «against human dignity», and anyone disagreeing is facing an uphill battle. One could of course quote Ruth Macklin (1), Stephen Pinker (2) or

Ruwen Ogien (3); but that is not going to help and may even make one's motives morally suspect. Public bioethics is often expected to follow, or indeed promote, moralistic conventional wisdom.

NEK-CNE's work on preimplantation genetic diagnosis (PGD) provides a good example of this tension. The ethical dilemmas of PGD were very much present on NEK-CNE's agenda during my tenure as a member. Moreover, it is currently the only topic on which the Commission has issued two official pronouncements (no.10/2005 and 14/2007, see the NEK-CNE web page) (4). The first report proposed a cautious and partial lifting of the wholesale ban on PGD existing then and now in Swiss law. The second discussed newer issues related to PGD, especially the «saviour baby» controversy, and concluded that the commission was deeply divided on the ethical acceptability of this practice.

In the bioethics literature, the use of PGD to select a future child with the appropriate characteristics to act as a tissue donor for a pre-existing sick sibling has been abundantly discussed. While the controversy goes on, the accepting view is widely represented and has to some extent been translated

into public policy in a few countries, notably the UK (5–7). In contrast, from a Swiss perspective, that same view is typically seen as liberal and permissive in the extreme. Defending it in an academic context is no problem of course, but carrying these debates over into a political-ethical body, as I tried to do, feels like a mildly eccentric and perhaps futile exercise, since there is no realistic prospect that the dominant conservative stance in the political arena could budge in the foreseeable future.¹ Indeed not only does the law presently make PGD illegal for any indication whatsoever, but that particular ban is part of a solidly interlocking network of prohibitionist legislation outlawing the freezing of embryos, all forms of cloning, oocyte and embryo donation, the use of heterologous sperm in infertility treatment of unmarried couples ... several of these bans are based on an article of the Swiss constitution, no less (art. 119). That circumstance raises an additional high hurdle in the way of any legislative change. As a result, the role of the ethicist defending liberal and utilitarian positions in *Mitteleuropäer* public bioethics is mainly to call attention to contrarian views in a friendly way, without too many concrete expectations.

Going back to NEK-CNE and its discussion of PGD in connection with tissue typing, it may be initially surprising that this issue ended up being debated so extensively. In fact, the Commission was able to move beyond the usual knee-jerk Kantian response stating that the saviour child is being «instrumentalised», i.e. treated as means only and not as an end in itself. What pulled the Commission out of its moral comfort zone is that a concrete «saviour baby» case erupted on the Swiss media scene in 2006. A couple from Geneva had had a first boy, Noah, suffering from granulomatosis. It had been found that he could be saved by a stem cell graft from a compatible healthy donor. The couple went to Brussels to obtain PGD (which is legal in Belgium). As a result, the girl Elodie was born and provided the bone marrow graft for her brother. The transplant was performed in Switzerland and proved successful. This success story of a saviour child was widely publicized in Switzerland. Media responses were usually favourable to Elodie's and Noah's family, especially in the French-speaking part of the country. Thus the Commission experienced first hand how an abstract issue is transformed more or less deeply by having to face a specific human experience squarely. The whole Kantian language game of «being treated as mere means, rather than an end in itself», of «human dignity», and of «instrumentalisation», in which Central European bioethics feels naturally at home, suddenly seemed rather odd and foreign to reality. This per-

plexity shows through when comparing NEK-CNE's 2005 and 2007 reports. On the one hand, the saviour child is not the central concern of the 2005 paper, which does devote a rather balanced section to this issue (section 3.6). Still, in keeping with the central concern of Swiss debates that views any kind of embryo selection as dangerously close to eugenics, the clinching argument seemed to be that:

«In this context (i.e. PGD for tissue typing), the ethical evaluation of selection must take a peculiarity on board: while searching for characteristics that have nothing to do with the health of the future child herself and do not concern a disease of the rejected embryos either, some embryos were retained while others were excluded. This kind of selection practice is perceived as morally abhorrent by many Commission members and considered ethically blameworthy» (ref. 4, 2005 report, p. 48).

In contrast, the 2007 paper goes much further in criticizing conventional objections to saviour child practices and NEK-CNE expresses some dissatisfaction with arguments of its own earlier document. Furthermore, it is quite aware of the *paradox of concreteness* mentioned above. While describing the various contexts in which the saviour child issue is debated, it remarks:

«When examining these different *moral frames*² more closely, it is mainly the discrepancies between considering PGD «up close» (as by concerned couples and physicians), and considering it from afar (in the public debate) who become readily apparent.» (ref. 4, 2007 report p. 4)

The «instrumentalisation» argument is criticized more sharply than in 2005, much along the lines of what follows in the final paragraphs of the present paper. But in the end, the report can only take stock of the deep division amongst NEK-CNE members on the permissibility of saviour child uses of PGD and concludes by listing the two, more or less equally represented positions and their main arguments. Yet interestingly, the text adds a unanimous statement to the effect that:

«(...) parents who obtain PGD abroad in order to beget a child with the appropriate HLA type act on understandable and honourable ethical motives and deserve no moral or ethical blame. Those in the Commission that reject the legalisation of PGD for tissue typing justify their position with arguments of social ethics and do not question the individual decision of parents» (ref. 4, 2007 report, p. 16).

Finding a particular behaviour morally praiseworthy yet still wanting to outlaw it may raise a coherence issue that was not discussed.

1 A parliamentary majority expressed the intention of lifting the ban on PGD in specific limited situations, but certainly not to allow saviour children.

2 In English in the original text

At the end of the day, I was left with the impression that a major unsolved question raised by these debates on the saviour child was the relevance of the Kantian notion of instrumentalisation to human procreation. Throughout history, humans have reproduced for a variety of reasons. Or for no reason at all, when having sex without sparing a thought for the possible consequences. Today, the happy-go-lucky option is morally frowned upon by most moral authorities. So we are left to consider the many motives figuring in the first option:

- Having children to be supported in old age;
- Transmitting a legacy of material or immaterial assets, such as an estate, a professional tradition, a set of family values;
- Obeying religious or societal commands and/or pressures that mandate procreation as a duty, or at least consider it «the done thing»;
- Consolidating or repairing an ongoing relationship;
- Narcissistic motives, such as having a child in order to realise one's own unfulfilled ambitions, producing a genetically related offspring, procreating as a surrogate form of immortality;
- «Feel good» motives, such as expressing the couple's mutual love, or asserting one's confidence in life and in the bright future of humanity.

The list could go on forever. The point is that whatever the reason, future children are the means to fulfil some further goal, and are in that sense instrumentalised. As noted by David Benatar: «Children cannot be brought into existence for their own sakes» (8), since to the extent that prospective parents make a deliberate decision to have children, they do so in furtherance of some interests, their own or that of others. One could then draw the conclusion that procreation always falls short of the Kantian ideal (after all Kant remained childless, as far as we know). But another, probably more accurate, reading of Kant insists that persons should not be treated as means *only*. Complete instrumentalisation is what matters and none of the reasons listed above seems utterly incompatible with a child being also «loved for his/her own sake» once it exists. The conclusion is clear: The Kantian requirement is either too easily defeated or too easily fulfilled. It is a tautological and useless moral criterion as regards human reproductive choices. Actually, when compared to some of the more commonplace reasons that induce people to reproduce, the choice of parents contemplating the use of PGD to have a saviour child could be seen as quite admirable. Finally the debate on the saviour child is odd in another, more strictly legal, respect. Against earlier eugenic social policies, contemporary Western society considers having children as a basic human right, enshrined in the European human rights Convention as well as the Swiss Constitution.

That does not mean of course that public authority is indifferent to the welfare of children, but that any intervention aimed at protecting a child's fundamental interests is necessarily concerned with existing children, not prospective ones. In other words, scrutinizing a couple's private motives in begetting their own children, or questioning the ability of people to be competent procreators³ is clearly beyond the pale. Yet in the case of the saviour child, the State takes its authority to scrutinize these very motives for granted.

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Note: translations of quoted French and German texts are by the author.

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³ As opposed to competent and benevolent educators of an existing child, either their own or one that is given up for adoption.

Pre-implantation genetic diagnosis (PGD or PIGD) is the genetic profiling of embryos prior to implantation (as a form of embryo profiling), and sometimes even of oocytes prior to fertilization. PGD is considered in a similar fashion to prenatal diagnosis. When used to screen for a specific genetic disease, its main advantage is that it avoids selective abortion, as the method makes it highly likely that the baby will be free of the disease under consideration. PGD thus is an adjunct to assisted... Preimplantation genetic diagnosis (PGD) is performed for couples who are at risk of a specific inherited disorder (Table 1). The reproductive options for these couples are to remain childless, have no genetic testing on any pregnancy (reproductive chance), undergo prenatal or PGD, have gamete donation, or adopt. The couples who opt for PGD have already been diagnosed with their specific disorder, either because they have had an affected child, have a known family history or been diagnosed as an adult. PGD is not an easy option as it takes some time to validate the specific test for each couple; they have to go through IVF, and the success rates are only comparable to routine IVF patients. This current page is a general starting point for the topic of Preimplantation Genetic Screening (PGS, NIPT) also called Preimplantation Genetic Diagnosis (PGD) began during the 1990's as an alternative to other forms of prenatal diagnosis. "In the general population trisomies and sex chromosome aneuploidies account for approximately 70% of anomalies recognizable by conventional genetic analysis."