
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

_a Viewpoint

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. Indeed not only does the law presently conservative stance in the political arena could budge in the foreseeable future. Indeed not only does the law presently conservative stance in the political arena could budge in the foreseeable future. Indeed not only does the law presently conservative stance in the political arena could budge in the foreseeable future.1 Indeed not only does the law presently conservative stance in the political arena could budge in the foreseeable future.1 Indeed not only does the law presently conservative stance in the political arena could budge in the foreseeable future.1 Indeed not only does the law presently conservative stance in the political arena could budge in the foreseeable future.1

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 frames2 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 instrumentali
tisation 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 con-
sider 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 oth-
ers. 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 ac-
curate, 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 re-
quirement is either too easily defeated or too easily fulfilled. It is a tautological and useless moral criterion as regards hu-
man reproductive choices. Actually, when compared to some of the more commonplace reasons that induce people to re-
produce, 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 indif-
ferent to the welfare of children, but that any intervention aimed at protecting a child’s fundamental interests is neces-
sarily 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 procreators 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.

References

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

3. Ogien R. L’éthique aujourd’hui. Maximalistes et minimalistes. Paris: Gallimard; 2007. (It could be that the argument of the «need to protect human dignity» is political and conceptual rather than ethi-
cal. It would be one of these pompous word games thrown at the public’s face to impress, without the burden of coherence or justifi-
cations, pp. 188 –189)
4. Swiss National Advisory Commission on Biomedical Ethics (NEK-
CNE) web page; Available from: http://www.bag.admin.ch/nek-
cne/04236/04238/index.html?lang=en

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