Gene Therapies and the Pursuit of a Better Human

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As a philosopher interested in biomedical ethics, I find recent advances in genetic technologies both fascinating and frightening. Future technologies for genetic therapies and elimination of clearly deleterious genes offer us the ability to get rid of the cause of much human suffering, seemingly at its physiological root. But memories of past eugenics programs gone horribly awry (whether we speak of Hitler's program, California sterilization laws and practices of the 1920s, or even contemporary practices, such as attempts to work out deals that exchange sterilization for early prison release)[1] must make cautious our initial optimism for these generally well-intentioned programs. Most often the scientist proceeds in research with the best of intentions, but that does not make all scientific investigation worth pursuing.

Surely no one would dispute the claim that the aim of bettering humanity and/or our own children is morally acceptable. Indeed, most of us see as ideal a world in which every parent works toward improving the lot of his or her child, or the lot of all of our children. But while no one denies the importance of this quite general goal, we are still left with difficult issues about *how* we ought to proceed in addressing that goal. When we try to dodge diseases or disadvantages through genetic intervention, are we solving problems or just moving them to a different level? I want to briefly address two quite general questions in regard to this topic. First, what *means* should we take in trying to better our children? Second, how are we to decide what really counts as "bettering" them? I do not claim to solve these difficult issues here, but only to consider some ways we might approach the problems.

Consider the various ways in which we try to better our children. First and foremost, we try to educate them. That is, we provide public education for all children with the intention of teaching them not only how to read, write, and do arithmetic, but also how to function in this society and how to make important decisions in their lives. No one questions this means to bettering our children, unless they find fault with particular styles of teaching (for instance, they see the teacher as indoctrinating a particular view rather than presenting basic facts and promoting the child's own rational critical faculties in assessing those facts). Generally, as long as the education exercises the child's mind and allows the child some autonomy in regard to how he or she will understand the material, this means of bettering is considered morally acceptable and even required.

In addition to education, we find it morally acceptable to better children by giving them appropriate medical care. If a child needs surgery or a painful treatment to survive or to thrive, we allow ourselves room to do what is "best

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for the child" even if that may involve unavoidable pain that the child is not able to consent to. Furthermore, we often go beyond merely treating clearly defined diseases and actually allow enhancement of our children in the medical setting. We regularly give our children vitamin supplements, vaccinations, and dental enhancements (e.g., braces), and we generally do not blink at such interventions.[2] Thus we have no clear moral concern with imposing medical treatments paternalistically, so long as we are fairly certain that we are promoting the child's best interests.

There are no doubt numerous other ways that we try to make things better for our children and future generations. Many of them are indirect: we try to balance the national budget (or at least keep it under control); we try to pass legislation that will save the environment and preserve a fair quality of living for future generations; and we put federal and state money into exploratory research that is unlikely to produce immediate results but may lead to improvements in future lives. So whether we are trying to enhance children themselves or their environment, we are generally quite at ease with working toward improvements.

But how do genetic therapies fit into this classification? If we are speaking of somatic cell therapies (performed on the body cells of a fetus, infant, or adult, so that the genetic changes will not be passed on to the next generation), then we at least have an identifiable being who may be benefited by the changes; but if we speak of germline genetic therapies, performed pre-embryonically, then what is in question is who will come into existence, and we find ourselves in the Parfitian paradox of future generations.[3] Should we be compelled to try to make things better for unidentifiable future persons? What could the compelling reason be? Without wading through the vast literature debating this topic, I think it is safe to say that most of us are at least willing to admit that duties of beneficence and intuitions about morality suggest that we do care about these future people (whether or not we are required to do so by rules of justice). But in trying to work things out for future people (or even for young children who are not considered competent to decide for themselves), we must decide what kind of interventions are morally legitimate and most likely to be truly beneficial.

If we think that a genetic therapy will benefit a fetus or child, should we perform that therapy? The initial response might appear to be a resounding yes. This sort of treatment appears to get to the root of the problem and eliminates the need for any suffering from the disorder. Some common arguments posed against genetic interventions generally have been rather soundly disposed of in the relevant literature, e.g., arguments from playing God, from messing with nature, from the inevitability of slippery slopes.[4] But in a society that tends to overvalue the quick fix solution, we might do well to exercise some caution even here.

First, we might get unexpected results. If we perform genetic therapies to remove or change a clearly deleterious gene, then we might find that other important physical or psychological traits were also controlled by that gene (or by its influence on another gene or its expression). The commonest example here is the link between sickle cell trait and resistance to malaria. Another such link commonly discussed in the literature is that between creativity and various forms of mental illness.[5] Although we may be interested in relieving the suffering caused by the expression of certain genes, we are not yet certain what else we may be removing or changing inadvertently. Although these are certainly reasonable worries, even with such possibilities, treating painful and restrictive genetic disorders (e.g., Tay-Sachs or cystic fibrosis) might be worth the risk, so long as traditional rules regarding informed consent for clinical trials are respected.[6]

Second, we might be losing something valuable if we are able genetically to engineer around our problems. Erik Parens, for instance, suggests that part of what we value about humanness is our fragility, and the capricious nature of our lives, which necessitate our taking care of one another in times of need.[7] If we are able to use genetic engineering to get rid of this fragility (or at least to change the kind of fragility or to make people less willing to feel sympathetic to one who is fragile), then we may inadvertently destroy something very valuable. This is not to say that we must keep people suffering so that we can be caring creatures, but only that we might lose part of what makes us really appreciate our lives.[8] Parens has tongue-in-cheek suggested that we might all vote to make it so that no one had to experience adolescence as we know it (it is painful to go through and it is painful to be around those who are going through it), but he also notes that most of us place value on the process of working through such a time, and that effort is part of what makes us appreciate our adult lives.[9] Thus he counsels caution in our eagerness for genetically eliminating *anything* that appears to cause pain or discomfort, and a deeper analysis of what it is that we receive from the experience of living with disadvantages and diseases.

This brings me to my second issue: How are we to decide what is to count as "bettering" children? Few of us would dispute the claim that eliminating Tay-Sachs disease or Lesch-Nyan syndrome or cystic fibrosis would count as an improvement for future generations. A future in which no one has to suffer from these debilitating diseases seems undeniably worth pursuing. On the other hand, disability rights advocates are quick to point out practical problems with holding this view without devaluing existing persons with those diseases.[10] Even if we can conceptually distinguish between the value of individuals with disabilities and the relative value of bringing such individuals into existence given other options,[11] in practice, public attitudes toward such individuals are likely to be prejudiced and will likely affect public financial support of the disabled.[12,13]

Even if we could reach agreement about the value of genetically intervening for clear cases of debilitating disorders, there are some physiologically or genetically based conditions that offer disadvantages to children in our society that might not so clearly be candidates for intervention. What about cases in which the real cause of the disadvantage is located in unjustified societal prejudices or values? For instance, children who are shorter than average (and grow into shorter than average adults) have a smaller statistical chance for success in classes and in athletics (and ultimately in the job market) because of the biased perception of them based on their inferior height.[14] Physicians who offer growth hormone treatments treat the physiological symptoms of shortness as a way of solving the social problem for the child. But the community is then allowed to continue its arbitrary preference for taller people. In this case, society is at fault for creating the disadvantage—solving the real problem seems to require addressing societal values, *not* just engineering a way around the problem. This may seem obvious, since when height is the feature in question, there is no absolute