

# 'Healthy' human embryos and reproduction

## **Making embryos healthy or making healthy embryos: how much of a difference between prenatal treatment and selection?**

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### **I. Introduction**

In previous work, we have argued that the professional endorsement and parental acceptance of prenatal selection for or against particular characteristics (such as sex or health) display and perpetuate attitudes inconsistent with the ideals of familial welcome and societal inclusion (Asch and Wasserman, 2005). To reject a parental relationship with a future child on the basis of knowledge of a single characteristic is to allow that characteristic to obscure or to eclipse all other features of the future child. In allowing the part to stand for the whole, the prospective parent displays a problematic 'synecdoche'. Any trait-based selection conflicts with the ideals of unqualified welcome and inclusiveness to which prospective parents and society as a whole should aspire. And when the single characteristic is an impairment, the exclusive reliance on its detection as a basis for exclusion is a stark form of stigmatization: the rejection of a child as the bearer of a feared or despised trait.

In suggesting that prenatal selection against disability typically reflects stigma-driven stereotyping, we have not had to resolve the issue of whether impairments, or certain impairments, are inherently disadvantageous.<sup>1</sup> All we require is the recognition that an individual can live a rich, worthwhile life with almost any impairment. Even in today's imperfect and still-discriminatory society, people with disabilities can and do lead fulfilling lives and contribute in manifold ways to their families and communities. And even if such prenatally diagnosable conditions as cystic fibrosis, muscular dystrophy, sickle-cell anaemia, Down syndrome, and fragile X limit a person's lifespan or life opportunities, a person with any one of these conditions can participate in a wide array of valuable activities

<sup>1</sup> In this chapter, we will generally use 'impairment' to refer to deficit in or variation from normal or species-typical physical or mental function or structure; 'disability' as the social classification or condition of people with significant impairments. This admittedly imprecise usage roughly corresponds to the prevailing distinctions drawn in the law and disability scholarship.

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and relationships. And that, we contend, is enough to make parental selection against those conditions morally problematic.

Enter the possibility of prenatal therapy to modify an embryo or fetus. Although still in its early experimental stages, prenatal gene transfer may prove to be among the first feasible forms of genetic therapy. As a 1999 commentary in *Nature Medicine* argued (Scheider and Coutelle, 1999), prenatal therapy offers several advantages over postnatal therapy, because it may be able to prevent the expression of many genetic diseases and because of the greater ease of introducing genetic changes into a still-developing organism. In this chapter, we will consider a subset of the ethical issues likely to be raised by prenatal gene therapy even if it is safe, effective, and free of the risk of germline modification.

How should we evaluate such interventions? We suggest that the professional enthusiasm for these prenatal treatments reflects all of the harmful attitudes towards people with disabilities and life with disabilities to which we have objected. The desire to spare parents the 'tragedy', 'burden' and 'suffering' of having a child with an impairment is no less misguided when the misfortune is averted by prenatal therapy than by selective abortion or selective implantation. Still, even if the attitudes motivating the development of prenatal therapy are far from ideal, should we throw away the treatment because we want to change the attitudes? In assessing the prospect of prenatal therapy, we confront a host of difficult questions.

Can we endorse prenatal modification without accepting that the impairments it corrects are inherently disadvantageous? Must we conclude that future persons would be served better, in some sense, if they were not to have an impairment? If we conclude that prenatal prevention or correction is not problematic in the same way as prenatal selection, are we then rejecting the 'pure' social model of disability and holding that it is desirable, even morally imperative, to preserve the potential for certain human capacities?

Can we understand prenatal modification in a way that places it in the same category as other actions that we expect prospective parents to take on behalf of their children-to-be? In general, what sorts of duties do prospective parents have towards the children they intend to raise? Does the recognition of such duties conflict with a woman's moral 'right to choose', or does that right apply only to choices about whether to have a child, not to choices about how to protect or benefit a child the woman decides to have?

Alternatively, is prenatal therapy or gene transfer better analogized to the actions people with and without disabilities take to preserve, improve or restore their children's health after birth? If parents would be expected to ensure that a newborn infant with spina bifida received surgery to close the spinal opening, or if parents of a two-year-old with a heart condition would be expected to seek corrective surgery to ameliorate its effects, is prenatal surgery for these same conditions equally incumbent on prospective parents? Are all such prenatal interventions the kind of health-preserving actions that we expect parents to undertake for their children?

In addressing these issues, we consider an idealized type of disability – the simple absence of a sensory, motor or cognitive function, without the pain or the progressive character of disease. We argue that at least in the case of such 'static impairments', the answers to these questions are not obvious and require further analysis and deliberation. Because it is difficult to evaluate the disadvantages associated with static impairments, and because most genetic impairments are not static, we do not offer any conclusion about the morality of prenatal therapy for all potentially disabling traits. We leave open the possibility that our analysis of prenatal intervention to prevent static impairments could also apply to other conditions for which prenatal therapy may be sought. We hope the considerations we

raise will help parents and healthcare professionals more realistically assess the costs and benefits of prenatal therapies as they become safer and more effective than they are at present.

It is instructive to begin by considering the attitudes towards disability that have motivated the quest for prenatal therapies. A 1982 article in the *New York Times* on the advent of prenatal therapy (Henig, 1982) revealed that the attitudes of the field's pioneers differed little, if at all, from the attitudes motivating the concurrent development of prenatal testing for disability. A leading National Institutes of Health (NIH) scientist was quoted as saying, 'As people begin to seek help – all those men and women who don't want to sponsor the life of a damaged individual – more doctors will try to provide what help they can to give the fetus a reasonable chance of a good start in life.' A pioneering fetal surgeon stated that 'My biggest worry is that we might take a lesion that is lethal and correct it just enough that it is not lethal but is still incapacitating.' Why this was his biggest worry is suggested by another surgeon's question about a failed attempt to treat fetal hydrocephalus, which caused the fetus to bleed to death: 'This, of course, is the worst nightmare of fetal surgeons: that their efforts will lead to the death of a fetus. "But I wonder", Dr. Nelson says, "is he any worse off now than he would have been if we hadn't treated him at all."' The article also raised the related issue of parents' willingness to subject a fetus to life-saving but also life-threatening surgery with little prospect of complete cure, a concern that was expressed under the rubric of informed consent: 'The parents do not evaluate in any clear, rational way the fact that the baby could still be very sick when it's born, says Rita Douglas, the genetic counselor' – it seems that the significant possibility that the child would be left disabled made it irrational for parents to choose risky but life-saving surgery.

Prenatal surgery (e.g. to close up neural tubes) may have been a much riskier business in 1982, when it was undertaken by a higher proportion of women who opposed abortion, or who regarded the uncorrected impairment as only marginally better than death. But it is doubtful that the grim appraisal of life with a disability that informed the 1982 debate has changed much in the intervening years. Depressingly similar sentiments were expressed in the debate over the 1998 proposal by William French Anderson to begin research on prenatal gene transfer. The Council for Responsible Genetics was reported as describing Anderson's proposal as 'a step toward a pernicious use of prenatal genetic engineering to create "designer babies"'. Other commenators were less concerned about the success of prenatal therapy than its potential failure, regarding severe disability as worse than death. Anderson felt that 'the worst thing that could happen would be to help these fetuses to be born alive but with serious anomalies'. A 1999 report on prenatal gene transfer by the NIH Gene Therapy Policy Conference expressed worries that the partial correction of otherwise fatal conditions would have the potential to make a 'tragic situation even worse' (National Institutes of Health [NIH], 1999).

These examples dramatize what medical experts and some of society's opinion-shapers believe about disabilities and the lives of people who live with them. Prenatal testing, preimplantation genetic diagnosis (PGD) and embryo selection were developed in large part because of these beliefs (Cowan, 1994). Thus, it is hardly surprising that the medical profession would look to prenatal therapy to avert what it sees as lives filled with suffering and tragedy. Many disability scholars have argued that these attitudes are exaggerated and misinformed (e.g. Silvers, 1998; Asch, 1989, 2003; Scully, 2008). But would a more realistic appraisal of life with various impairments lend any support to prenatal therapy to correct them? To assess the need for, and the value of, such therapy, we must address the questions

of whether and how it makes sense to speak of impairments as different from other human variations, and whether and why it is bad to have impairments.

## II. Is it inherently bad or harmful to have an impairment such as blindness?

Blindness is the impairment philosophers have most often used (without explanation) to illustrate their claims about the impact of disability on well-being. At the outset, we want to explain our reluctance to follow their lead. One reason is that by focusing on a single impairment, we risk the rejoinder from sceptics that whatever we claim about blindness does not apply to any other prenatally diagnosable and potentially modifiable trait. The second reason is that one of us (AA) is blind, and we are uncomfortable about making this essay overly personal. Yet in order to join issue with philosophers who have written about disability, we must overcome our reluctance and talk about the same impairment. In making claims about blindness, those philosophers are evaluating it from their vantage point as people who have always been sighted. By incorporating the perspective of someone who has always been blind, this chapter will be no more subjective, and arguably better informed, than those essays it challenges (Magee and Milligan, 1996).<sup>2</sup>

Why would most readers regard a life with blindness as worse than a life with sight? The capacity for sight provides the opportunity to gain information about the natural world and about people, and it is a source of aesthetic enjoyment. Along with Martin Milligan (Magee and Milligan, 1996), we suggest, however, the benefits of sight can be appreciated without concluding that life without sight is worse than life with it. Although it may be difficult to regard blindness as a human variation of no more consequence than having blond rather than brown hair, we are not compelled to regard it as a bad or a harm. To explain this claim, we must first address a stronger claim that blindness – like hair colour or eye colour, baldness or left-handedness – is a neutral human variation.

### Impairments and neutral traits

What does it mean to call a trait ‘neutral’? Does any human trait or variation qualify as a neutral? These are not easy questions. As Jackie Leach Scully (2008) points out, we lack a neutral language to describe structural and functional variations, a language that does not assume that such variations are disadvantageous or harmful:

To impair is to reduce, weaken in strength, etc. The definition does not include the possibility of a morphological variation that does not have a harmful impact ... on the limb or organ and/or on the subjective experience of the individual. This is a significant gap because there needs to be a space to describe a variation in body form or function prior to making judgments about its effects.

(p. 32)

<sup>2</sup> For an intriguing conversation about how a thoughtful philosopher who is blind thinks about sight, and the contrast of these views with those of equally thoughtful persons who are sighted, see the interchange of letters between Bryan Magee and Martin Milligan in *On Blindness* (Magee and Milligan, 1996). Milligan discusses his own views in depth and also refers to the views of many others who have been blind from birth or early life, as well as to the views of people who are now blind but who have had sight for considerable portions of their lives. Although he does not claim a unanimity of beliefs, he does suggest that his views are not idiosyncratic. He argues for the importance of learning how people with a particular static impairment think about the meaning and impact of that impairment on their lives. Our citations to *On Blindness* reflect our strong endorsement of Milligan’s general approach to understanding disability rather than his particular account of the experience of blindness.

Hair colour or eye colour, the absence of hair, and handedness are often given as examples of phenotypic variations with no impairing effects. One way of assessing neutrality in this sense is, very roughly, in terms of an analysis of variance: we can regard variations or traits as independent variables, and test whether they have any 'main effect' on the dependent variable of well-being or quality of life – however defined. In this sense, eye colour and hair colour seem neutral; because, across the range of social environments we are concerned about, average well-being does not seem to be affected by whether a person is blond- or brown-haired, or has blue or brown eyes. People of all hair colours are able to function in common activities, and hair colour is not equated with the capacity to assume the social roles or obligations of worker, community member, citizen, friend or family member. Some people receive more aesthetic pleasure from blond than brown hair, but many others like both hair colours equally, have no strong preference or prefer brunettes to blondes.

The effects of handedness may not be as clear cut. Left-handedness is less prevalent in our society than right-handedness, and tools and other features of the built environment may be less convenient for left-handed people because they have been constructed with right-handed users in mind. But these are small inconveniences, swamped by larger commonalities. Society expects the left-handed child or adult to be capable of participating in and contributing to the world to the same extent as his right-handed brother. At this writing, we know of no claims that either hair colour or handedness affects a person's overall quality of life – a person's opportunity for experiences, achievements and relationships.

The denial that blindness is a neutral trait in this sense could be supported by a similar analysis. In the range of environments in which prospective parents can expect to raise their children, people who are blind probably experience problems that people who are sighted do not. Several factors may contribute to this likely difference. First, sight, not blindness, is species-typical; blindness, especially the total absence of vision, is extremely rare, whereas variations in hair colour are quite common. Thus, even with legally mandated accommodations, less 'demographic' pressure will be exerted to design the built environment for people who are blind than for people whose minority traits are more common, such as left-handedness. Moreover, even in a society with strong anti-discrimination laws and norms, people who are blind will be uncommon enough that responses of social discomfort, awkwardness, fear and avoidance are very likely to mark their initial social interactions and to impede forming and maintaining casual social relationships, friendships and intimate relationships.

These differences will not disappear even if we restrict ourselves to societies that are more committed to inclusion than our own is at present. Stigma, awkward interpersonal relationships and recalcitrant vestiges of institutional discrimination will probably continue to differentiate the reception of people who are blind from the reception of those who are, for example, blond when they are present in schools, workplaces or social gatherings. A child or adult who is blind can be expected to experience significant discrimination in some aspects of her life and from some segments of society. In contrast, we are not aware of any prejudice towards blond children.

The profound, pervasive role of stigma in the negative appraisal of impairments was pointed out by Jacobus tenBroek more than 50 years ago (1956). He imagined how debilitating the impact would be on the lives of bald people if they confronted the same social attitudes and assumptions faced then, as now, by people who are blind. To those who would question the plausibility of the comparison, tenBroek had the following rejoinder:

Is it not surely ridiculous to imagine that any civilized society could so baldly misinterpret the character of those who are not blessed with hair on their heads? It may be! But civilized society has

always so misinterpreted the character of those who lack sight in their eyes; and on a basis of that misinterpretation has created the handicap of blindness. You and I know that blind people are simply people who cannot see; society believes that they are people shorn of the capacity to live normal, useful, productive lives, and that belief has largely tended to make them so.

And yet if prejudice alone were the only general way in which a child's life would be expected to go worse because of blindness, we might regard it as unnecessary or inappropriate for parents to prevent or correct blindness. We might rather insist that society reform its attitudes, practices, and institutions. In fact, we and others have argued much the same thing in criticizing the use of PGD and prenatal testing to select against the births of children with particular characteristics: don't screen out the child, but create a family and society that will welcome him and enable him to flourish.

### Impairment, lack of capacity and lack of opportunity

The comparison of baldness to blindness also suggests, however, that traits may lack neutrality for more than one reason, and that those reasons may be relevant to their prenatal modification. Baldness, the absence of hair, is an attribute to which others respond; blindness, the absence of sight, is both an attribute that evokes responses in others, and the absence of a capacity to discern certain facets of the human and natural world. Baldness and blindness both have consequences for how life goes, but blindness has greater consequences in more domains of life, which is not only because blindness is more stigmatized than baldness but because it is inconvenient in some environments and limits some classes of experience. Thus, although neither trait may be strictly neutral in the sense we have been discussing, the explanation for their non-neutrality is different. Baldness, like dark skin colour, is not a neutral trait because it is not associated with average well-being in the environments we can be expected to encounter. But that lack of neutrality, for baldness as well as for skin colour, can be almost entirely attributed to a lack of 'neutrality' in the design of the society and the attitudes of its members. The remaining biological differences (e.g. slightly greater susceptibility to sunburn and skin cancer) are trivial in the aggregate.

In contrast, some of the significant differences associated with blindness do not appear to be attributable to a lack of environmental neutrality or to be eliminable by environmental reconstruction. These differences may make it seem more appropriate to talk about 'correcting' blindness than blondness, or even baldness. Even in a utopian, non-discriminatory society where environmental features have been revamped to make it easier to get information about the world without having vision, blindness is likely to affect more aspects of life than blondness or baldness. As we noted earlier, the capacity for sight enables people who have it to apprehend many features of the natural and constructed world that afford both information and enjoyment (Magee and Milligan, 1996, letters 2, 4 and 5). Sight provides one more channel of information for a person to know of an approaching lion in the jungle or an approaching robber on a deserted street. Seeing distant dangers may give a person enough time to escape certain harms. Leaving the realm of danger, consider the more common aspects of life: catching a friend's worried expression that could prompt you to go out of your way to inquire about what might be going on; finding a vacant seat in a crowded room near someone you want to talk with and avoiding the seat near another person whose company you don't enjoy. The benefits of sight are, of course, not only practical: consider such experiences as delighting in the vastness of the mountains or sky, the colours of autumn leaves, the paintings of Picasso, or the smile on your child's face. People who experience these sights receive exquisite enjoyment. The reader who feels that

going through life without such opportunities, or being suddenly deprived of them, would greatly diminish life cannot imagine that blindness is neutral; for such a reader, blindness has vastly more impact than does a particular hair colour, or even the absence of hair.

It is simply not plausible to claim, as some sympathetic observers suppose, that all or most of these absences are 'compensated for' by other biological capacities. People who are blind may learn to become better listeners, but they do not start life with greatly superior auditory capacities or extraordinary perspicacity. For this reason, a lack of sight cannot plausibly be claimed as having the same neutrality as hair colour or eye colour. But recall that our dependent variable was not an index of performance but the far richer and more amorphous concepts of well-being and quality of life. And although there are experiences blind people cannot have and activities in which they cannot participate, it is not clear that their lives go any worse than those of sighted people.

Even if the capacity for sight provides people with information and enjoyment that cannot be acquired through any other modality, and even if it offers many worthwhile experiences and a wealth of information, sight is nonetheless only one source of information and enjoyment and only one of the capacities that contributes to a satisfying life. Although a person who is blind cannot catch her friend's worried facial expression, she pays attention to other behaviours and signs from her friend and knows that she must find other ways to uncover that information. If the person who is blind knows that he is looking for particular colleagues or acquaintances, he can alert anyone telling him about vacant seats that he is trying to find or stay clear of certain people. The blind person will not enjoy one class of aesthetic experiences, but countless others are available (e.g. weaving, sculpture, music, ocean breezes). Those who insist that impairments foreclose opportunities for knowledge and experience, and that foreclosing such opportunities diminishes life, focus too narrowly on the specific activities that are unavailable. They fail to see activities as means to an end (e.g. eye contact as a means of communicating or achieving intimacy) or as instances of a broader good (e.g. visual appreciation as a form of aesthetic enjoyment).<sup>3</sup>

As a concrete example, consider Tom Sorrell's claim in 'Disability without denial' that some congenitally blind people consider that the lack of eye contact 'is a dimension of loss in a relationship with a sighted partner' (Sorrell, 2007, p. 419). The word 'loss' is misleading here because the relationship would never have had that dimension. The sighted partner is presumably the one who feels the loss of a means of communication he has been accustomed to in other relationships with people who can see. The claim appears to be that any intimate human relationship – or at least a romantic relationship – will be impoverished in a significant sense without eye contact, even a relationship between two people who are blind.

But is this claim true? It surely appears that similar levels of intimate communication are achieved through touch, speech, hearing and the sharing of physically, sexually and emotionally intimate experiences. Couples with one or both partners who are blind develop effective strategies for finding each other in crowds, extricating themselves from awkward social events and so on. Their strategies might be perceived by outsiders as 'compensatory',

<sup>3</sup> Our scepticism about the badness of congenital impairments does not rest on the naive view that what you don't know can't hurt you. Contrary to the common belief that people born without certain capacities cannot understand how losing them is intolerable because such people never knew the joys of full health or mobility, disabled individuals are made keenly aware of what they do not have. They are told all their lives what they are missing, sometimes just descriptively, but often in tones of pity and condescension. They are surrounded by people enjoying paintings they don't see, music they don't hear, sports they don't play. It is ludicrous to think that anyone born with a disability who is not filled with sorrow and rage at her condition is simply denying the glories of the world she doesn't know.

and might well take a little more effort and resourcefulness than sighted people would need to achieve similar objectives, in part because social conventions are developed by and for the sighted majority. But intimate tactile and verbal communication should not be seen as a way of compensating for a lack of intimate visual communication. People who can see use visual communication with one another because it is effective and rewarding.

However, there is no reason to think that visual means are superior to tactile or auditory means. It would be difficult to argue that visual contact provides a deeper or more direct source of intimacy than tactile or auditory contact without falling back on suspect or metaphorical claims, for example, that the eyes are the windows to the soul. Obviously, a person who is blind will rely on tactile or auditory contact, not visual contact, but this reliance can only be regarded as compensatory because a sighted majority gives privileged status to visual contact as a means to, or aspect of, intimacy. Tactile and verbal communication appear to be on a par with visual communication. Two people who used visual, as well as tactile and auditory communication would have one more method through which to express or achieve intimacy, but the number of methods available need have no correlation with the degree of intimacy experienced.

Our suggestion is that neither sight, nor any other single sensory–motor capacity, should be thought of in Daniels' terms (1985), as an all-purpose good, essential for virtually any life plan, but rather as one among many means of attaining some of life's rewards. In today's far from utopian world, people who are deaf create poetry and theatre in American Sign Language, people with mobility impairments become involved in adapted or typical athletics, and persons with autism and Down syndrome increasingly articulate their own views of their needs and experiences. Realms of activity often thought unimaginable for people with disabilities are now components of many of their lives. Sight, speech and walking all make possible certain typical human experiences, but they are means to, or specific forms of, ends such as learning about the world, communicating and getting from place to place. Humans have been inventing and discovering other means to accomplish those ends all through history, and we suggest that the ends are more important than any one method of accomplishing them.

The broader claim we are defending might be put as follows: human beings enjoy a fortunate redundancy in many of the capacities that are instrumental for, or constitutive of, valuable human goods and activities, from intimate relationships to rewarding work. Humans with a standard complement of senses and motor functions rarely use all of these functions in achieving such goods, and humans lacking those skills can only use some. But those are usually sufficient. If they are, all that the latter humans lack is the same range of options. Our view allows for cases where a human lacks a minimally necessary subset of capacities for some important good. But this view suggests that such cases will be rare and that, given the variety and elasticity of the ways humans have of achieving valuable goods, we should be wary of claims to have identified such cases.

This view rests on a broad individuation of human goods that treats both the appreciation of paintings and the love of music as types of aesthetic experience. If they could not be grouped in this way, then a person who could not see would necessarily lack the capacity for an important human good. We have no general argument for broad individuation, except to deny that it is special pleading; to insist that it reflects well-established and widely accepted ways of categorizing human goods, for each of which specific arguments for broad individuation can be made.<sup>4</sup>

<sup>4</sup> There is one respect in which even someone sympathetic with this account might regard even a single impairment as worse than none. An impairment may place the individual at greater risk of being unable to realize



Of course, however broadly we individuate goods, the absence of a sensory or motor function reduces the number of ways in which one can achieve those functions. But as we have argued earlier, the number of options one can choose from is only weakly related to the odds of success or the value of choice. A person may be marginally more likely to find an option he likes with more to choose from. But given the ‘adaptiveness’ of preferences, it seems unlikely that a person with a single sensory or motor impairment will not be able to find a satisfactory option for realizing almost any important human good. It also seems unlikely he will be unable to find an option that is roughly equal to, or on a par with, the best options foreclosed by his impairment. Moreover, even with limited options, he is likely to have enough to make his choice meaningful. He is unlikely to be ‘settling’ for whatever he can get, or to be acquiescing rather than actively selecting from a significant range of options.

No person in the world is likely to be interested in all of the physical, intellectual and aesthetic experiences the world affords. Even the voracious reader will not delve into every book written in every language or even in her native tongue. No devotee of classical music will have the time to study every available work composed since the twelfth century. The serious athlete is unlikely to become proficient at every known sport or game played in her country, much less to discover the pleasures of games enjoyed on other continents. No proponent of the opportunity range or the ‘open future’ expects anyone to take advantage of all that the world offers (Feinberg, 1980; Dworkin, 1988).

We must, of course, distinguish the absence of valuable capacities and opportunities from distress of losing parts of life we prize and distinguish our concerns about particular capacities from our concerns about loss and disruptive change. The loss of cherished capacities and activities is, in general, a bad thing, but its badness should be understood in terms of loss, disruption and discontinuity, more akin to the loss of a close friend or a beloved home than to the congenital absence of a sensory or motor function (Asch, 2003).

## Impairment, education and income

If blindness and kindred impairments should not be seen as inherently constricting, we need a way of understanding them to explain why most readers would regard parents as having strong reasons, or even a presumptive moral obligation, to prevent or correct these impairments in their fetuses. If impairments are not inherently bad, why do we promote good prenatal care in women and promote good healthcare in the general population? To address this question, we seek an analogy that suggests or explains how impairments can be seen as deficits worth modifying without being seen as harms or bads. We will consider one promising analogy: of physical or mental impairments to educational and material ‘impairments’, to see whether we can draw a distinction between bads or harms and the absence of goods or benefits, and to place certain impairments squarely in the latter category.

The disability rights movement has analogized disability to race or sex, contending that the presence of a disability is, can be and should be irrelevant to attaining access to societal participation (Asch, 2001). We still endorse this analogy in many contexts and believe that the further enforcement of civil rights laws and the resulting environmental reconstruction will narrow the gaps in education, employment and civic participation that exclude many people

important or essential human goods. If intimacy can be achieved with sight, hearing or touch, then a blind or deaf individual has only one sense to spare, and a deaf-blind individual has none to spare. Although this vulnerability to loss is not a negligible concern, it is merely one of the myriad risks that people face. If this is all that is wrong with a single static impairment, it deserves to be regarded as more of an inconvenience than an evil.

with disabilities. But for purposes of discussing bioethical issues, such as prenatal modification or access to healthcare resources and services, we propose that education and income are better analogies for disability. Most of us value a certain level of education and a certain amount of material comfort and suspect that life below some level of either is difficult, deprived, and to be improved if possible. Like most of the readers of this chapter, we are middle-class academics and professionals who live in considerable material comfort and have had many years of education.

Nonetheless, we note that billions of the world's people lead lives they value and bring children into those lives, with considerably less wealth and less education than is common for people in the developed world. We can appreciate the goods of education and material comfort while still appreciating the lives of people who lack those goods. We can endorse increased literacy rates for children worldwide and applaud efforts to redistribute the world's resources to provide more for people who live in abject poverty, without pitying or condemning people for bringing children into lives with relatively little in the way of education or material goods. Their lives have other valuable goods. Impoverished people in Latin America, Africa and parts of the affluent United States may aspire to improve one facet of their lives, but they needn't believe that their present lives are bad.

In analogizing impairment to a lack of education or material resources, we are imagining that a person grows up with an impairment and never has a capacity that others around her have, just as many poor people and people without much education live among, if not with, people who have more of both wealth and schooling. People without some capacity or some good that others have may be well aware of its potential for giving them life satisfactions, but they usually do not hate or devalue the lives they have without those goods – relative deprivation theory notwithstanding (Crosby, 1982). Observers shouldn't either, nor should they condemn people for bringing children into lives that don't have greater education or wealth (Contrast this view with Green, 1997, who contends that a child with a genetic disability is psychologically harmed by being different from those around him.).

Several striking parallels emerge between limited education and poverty on the one hand, and sensory-motor impairments on the other. First, the absent resources or capacities are clearly valuable. Like sight and hearing, educational and material abundance can be rewarding. Indeed, literacy is often touted as opening up vast new worlds inaccessible to the unlettered. Second, despite the obvious value of education and income, lives without those goods can go as well as lives with them. We have little reason to doubt that the best lives of our illiterate forebears, living just above subsistence, went as well as, or incommensurably well, on any plausible metric of well-being, as the best lives of our educated and wealthy contemporaries. It may be true that our ancestors only fared as well as they did because illiteracy and poverty were so widespread, but their flourishing is enough to belie the claim that those conditions are inherently or intrinsically bad. Third, as this population effect suggests, much of the bad or harm that is associated with a lack of education or material resources arises from demographic and social circumstances. To be poor or illiterate in a literate, affluent society is to be needlessly excluded from many valuable social activities and to be shunned or pitied by many of the majority possessing those goods.

We regard the advent of near universal literacy and the dramatic reduction in poverty as good things, while recognizing that many lives would have gone just as well without them. Despite our desire to confer these goods on many of those people that lack them, we do not regard their absence in many circumstances as a bad or harm.

The admittedly inchoate understanding of impairment shaped by this analogy can also be sharpened by contrast. It is useful to distinguish impairments – the mere lack of a capacity or function – from the diseases, disorders and injuries from which they often result, and of which they are often effects or symptoms. This distinction, however artificial in practice, can help us to see what it could mean to say that although a capacity or function may be a good, the absence of that capacity or function need not be a bad or harm.

## Static impairments and non-comparative harms

Several reasons exist for distinguishing the mere absence of sensory, motor, or cognitive functions – ‘static impairments’ – from the progression, pain, loss, uncertainty and death associated with chronic and acute diseases. First, a significant proportion of people with impairments do not have active diseases associated with them; they are, in that sense, healthy. Second, it helps us to critically examine recent accounts of non-comparative harm, which do not make this distinction. Third, the distinction lets us consider how specific functions contribute to well-being, in particular, whether they can be good to have but not bad to lack. We will examine the notion of non-comparative harm first, as a possible framework for our claim that certain types of impairment should be viewed as the absence of a good rather than a bad or harm. In the next section, we will suggest why that distinction might make a difference in the duty to prevent or correct.

It is important to emphasize at the outset that we are using the notion of static impairment as an idealization, for purposes of argument. We do not think it would be useful or appropriate to divide actual impairments into categories of ‘static’ or ‘dynamic’, which would lead to another line-drawing exercise fraught with the dangers of oversimplification and further stigmatization. But we believe it is useful to think of some impairments as mere absences of good, in order to explore – as we will only begin to do here – how viewing them that way affects the responsibilities and prerogatives of prospective parents.

Until recently, almost all philosophers employed what Joel Feinberg (1986) called a ‘counterfactual notion’ of harm and harming. A harm was a setback to an individual’s interests or well-being, compared with what it would, could or might have been; to harm an individual was to set back his interests in this sense. This notion has two problematic features. First, it treats harm simply as the opposite of benefit on a single metric of well-being, ignoring the complex and possibly incommensurable ways in which people do well or badly. Second, it requires the choice of a baseline as the alternative to which the individual’s state can be compared: How would he have done if he had continued at the level, or with the trajectory, he had achieved at some previous time? How he would have done if a given action had not been performed? What else would be changed if that action had not been performed? These are familiar problems to those acquainted with the counterfactual analysis of causation, and they lend appeal to a notion of harm that does not depend on comparisons to an elusive baseline.

As an alternative, several philosophers have recently developed non-comparative notions of harm (e.g. Shiffrin, 1999; Harman, 2004). These notions appeal to some aspects of common sense and ordinary language in treating ‘harm’ as a category that includes a number of discrete intrinsic bads, typically including death, pain, loss, frustration and impairment. A person can be made worse off without being harmed in this non-comparative sense, and a person can experience a harm, or be harmed, without being made worse off overall.

For those who make this distinction, its importance lies in the complexity it introduces into inter- and intra-personal trade-offs. Because harms and benefits cannot be adequately

assessed by placing them on a single metric of well-being, trade-offs among them may be harder to assess. In particular, harms to another may be harder to justify even if they leave the individual better off on some metric of well-being than he would otherwise be. Seana Shiffrin, an early proponent of a non-comparative notion of harm, has argued that although harms can be traded off against harms for individuals who cannot decide for themselves, imposing harms on them cannot be justified by 'greater' benefits (1999). Shiffrin takes this argument to imply that the creation of all children is presumptively wrong because it exposes them to myriad harms – death and the inevitable tribulations of life – without their consent. But one can reject her conclusion while still agreeing that the decision to expose someone to additional harm carries a greater burden of justification than the decision to deny him some good or benefit.

The problem with non-comparative accounts of harm lies in their details. The notion that certain states, events, or experiences are bad, if any are bad (to paraphrase Abraham Lincoln on slavery) has considerable intuitive appeal – how can we explain why something is bad without making an explicit or implicit comparison or association with pain, death, significant loss, humiliation, betrayal, profound failure, frustration and so on? But it is not at all obvious why disability or impairment should appear on this list. Specific impairments are certainly associated with all of the above harms, by biology or social arrangements. But they need not be, and mere association does not confer inclusion on the list; if so, life itself would be on the list. Shiffrin comes closest to a justification for including disability by characterizing all the items on the list as, roughly, involving a cleavage between the individual's will and experience. But it is not clear why having a static impairment would cause any more cleavage between one's will and experience than lacking such benefits as technical skills or disposable income – lacks that Shiffrin would not regard as non-comparative harms on Shiffrin's own analysis, the basis for classifying impairments as non-comparative harms remains unclear.

One might question the distinction between harms and the absence of goods by claiming that in the case of certain goods, the failure to reach a norm converted the absence of a good into a harm. In the case of impairments, the norm would be biological – some account of species-typicality, for instance. To have less of some capacity within or above the normal range would merely be to lack the good of a greater capacity, but to be sub-normal would be a harm. It is, however, doubtful that any account of biological normality could explain why a lack became a harm, especially if the norm was statistical. Why is falling two standard deviations below the mean a harm, but falling one deviation below only a lack, when it would take an expert to tell you where you fell? Even if the norm is not statistical, it is unclear why the failure to reach the minimum level of functioning specified by, for example, the best biological theory available should be a harm, when a slightly lesser shortfall was merely a lack?

Several factors, however, are loosely correlated with species-typicality that might convert a lack into a harm. The first, already discussed, is stigmatization – those falling conspicuously below a biological norm might be stigmatized, with all the unpleasantness following from that. But stigma is a contingent social fact, not inherent to a level of incapacity. Although stigma is certainly harmful, its medical prevention by selective embryo implantation or selective abortion raises the moral concerns we discussed earlier.

A more plausible claim is that a sufficiently high level of some capacity is necessary for some human good whose absence is rightly seen as a harm. Martha Nussbaum, for example, has argued that human flourishing has a number of constitutive capabilities, without which a human life cannot be said to go well (2006). If, for example, an impairment precluded the capability for forming or sustaining intimate relationships, it could be

regarded as harmful. Most people would regard having intimate relationships, or at least the capacity for such relationships, as a basic, irreplaceable human good, whose lack would be a harm however well one's life went in other respects.<sup>5</sup> The claim that a lack of capacity can preclude an arguably essential human good is most plausibly made with respect to extreme cognitive or psychological incapacities. A person who simply cannot re-identify others, or himself, cannot form anything worth calling an intimate relationship. Such incapacities are rare, however, and claims or assumptions of such incapacities are often exaggerated.

As we have argued, most important human goods, such as intimacy, are 'multiply realizable'. For this reason, we reject McMahan's claim that because acquiring such goods with multiple sensory-motor impairments is difficult, having multiple impairments must be worse than having a single impairment (2005). We also note that despite the difficulties McMahan assumes, people who are born with or acquire multiple sensory-motor impairments, such as deaf-blindness, cerebral palsy, stroke and 'locked-in syndrome' (Berczuk, 2007), have achieved and maintained sexual partner and parent-child relationships. McMahan's claim rests on the idea that individuals with single impairments can compensate for the lack of those capacities by relying on their unimpaired capacities, which he appears to regard as an inferior way to achieve important human goods, whereas individuals with multiple impairments often cannot.

Even if the difficulties faced by people with multiple impairments are as great as McMahan assumes, they can be accounted for in a way that does not require that we regard single impairments as bad in themselves. Only so many alternative ways are available for achieving important human goods such as intimacy. Many of those ways are incommensurably good; the choice of one does not 'compensate' for the inability to choose another. But some people have incapacities that preclude any means of realizing the good, or allow its realization in only an impoverished form. Such comprehensive preclusion is rare, however, and its existence does not suggest that the disadvantages of impairment are, as McMahan claims, additive. If you cannot realize a human good without one of three senses, you are not prevented from realizing it if you have, or use, only one of those three.

### III. Do prospective parents have obligations to modify an embryo or fetus to prevent impairment?

In *The Ethics of Killing*, Jeff McMahan (2002) considers the case of a pregnant woman who allows the fetus she intends to bear to lose the capacity for sight, knowing that he will fully adapt to his congenital impairment. On any plausible account of well-being, his life will be satisfying and of good quality; he will never regret his blindness, which will become a seamless part of his comfortable and rewarding life. McMahan assumes that most readers would regard the mother as wronging her child (if not her fetus) if she could have prevented, or avoided causing, his blindness without significant cost to herself or others. Most readers would likely think that the woman had acted wrongly by failing to prevent her child from becoming blind even if her reason were to avoid burdensome or uncomfortable preventative measures.

<sup>5</sup> Not everyone desires intimate relationships with partners or children, or even the capability for them; and it is abundantly clear from divorce rates and family estrangements that even those who desire intimate relationships can have enormous heartbreak, frustration and difficulty in their intimate relationships with others. Thus, we are not sure that we should make categorical judgements about the badness of a life without intimate relationships on behalf of someone who doesn't want such relationships or who feels that her life overall is preferable without them.

We agree with McMahan that most people would judge the mother to have wronged her child, but we believe that the foregoing discussion gives us grounds for caution about accepting this judgement. Unlike McMahan, we are prepared to find it mistaken, over-generalized or overconfident.

In the previous section, we suggested several ways of looking at static impairments that might reduce the moral urgency of correcting them prenatally. They should not be seen as bad or harmful merely in denying the future child some of the goods of life, and they do not preclude, and may not significantly reduce, the child's opportunities to obtain fundamental human goods. Even if the presence of a given capacity can be said to be better than its absence in abstraction or isolation, capacities should not be viewed in this way for purposes of assessing their prenatal preservation or restoration. Capacities should be assessed in the context of the lives of which they are part.

Admittedly, such an assessment will have a large element of speculation in the case of children who are not yet born. But even without knowing the particulars of their future child's life, the parents might reasonably conclude that having a static impairment such as blindness would not be a significant deprivation for him or her. They might be confident enough in the resources of their physical, family and social environments to decide that sight would be unlikely to make its life go substantially better – except in avoiding stigmatization and exclusion. And although the latter are important considerations, they are not straightforward ones, because environmental reconstruction and social reform are morally preferable ways of avoiding such evils, and correction may involve a problematic acquiescence or complicity.

We have also argued that with respect to the interests of the future child, as opposed to the interests of the society, static impairments such as blindness should be treated as the failure to confer, or the prenatal deprivation of, a good rather than the imposition of a harm. In making this claim, we are adopting a non-comparative notion of harm but rejecting the assumption of proponents of that notion that a static disability such as blindness should be regarded as a non-comparative harm. Rather, we contend that blindness is morally more akin to failing to give, or depriving one's fetus, of a very high IQ rather than an average IQ, and that such a prenatal deprivation may not itself wrong the child if it is done for reasons that do not reflect an attitude of indifference or disrespect to the future child.<sup>6</sup>

In arguing for a more careful and qualified assessment of static impairments, we have never denied that prospective parents will often have good reasons to correct these impairments prenatally, or that their failure to do so will sometimes be blameworthy. In this section, we consider the relevance of our reassessment of static impairments to the claim that parents have a very strong duty to correct static impairments in utero. We think it reasonable to provide an opportunity for prenatal modification to preserve sight, but we differ from others who would argue that ensuring it is incumbent on any prospective parent. Our view, we believe, is consistent with the social model of disability. We are aware of no social model disability theorist who argues against healthcare services for

<sup>6</sup> Thus, it would be insensitive or perverse for someone with a deep appreciation of the good of vision, like someone with a deep appreciation of the good of mathematical aptitude, not to want that good for his child. But he might want that good for his child, yet have morally adequate reasons for not obtaining it. His reasons would not have to be as compelling as those, if any, that would justify imposing or failing to prevent some harm to that child, such as a life of chronic pain or an early death.

infants, children or adults with or without disabilities because no holder of that model claims that having a disability is preferable to not having a disability. All that even the most 'extreme' social model adherents would claim is that a very substantial portion of what look like inherent disadvantages of disability can be traced to potentially modifiable social arrangements. These theorists are not claiming that in a more just society people would not enjoy the particular experiences that sight can give and would not want their children to have the opportunity for those experiences.<sup>7</sup>

We will proceed as follows: first, we will briefly consider several arguments that pregnant women or prospective parents have little or no obligation with respect to the fetuses they have created. The more plausible arguments merely suggest that those adults sometimes have weaker duties to prevent a given condition in their future child when that child is still a fetus than they have after it is born. We will then consider arguments that parents' obligations to prevent harm to, or avoid harming, their born children are not as strong or unqualified as often supposed; that parents have moral as well as legal latitude in raising their children that will sometimes make it acceptable for them to place their children at significant risk of serious harm. Our conclusion about prenatal therapy will follow a fortiori – if parents are morally permitted in some circumstances to place their born children at significant risk of harm, they are permitted in comparable circumstances to fail to confer important benefits on their unborn children. We will end with some suggestions about how the priority of avoiding harm bears on the assessment of risky prenatal interventions, in balancing potential harms and benefits to the future child.

## Claims of lesser duties to intervene prenatally

The strongest claim against duties to intervene prenatally also rests on the weakest argument: that if the fetus has little or no moral status, its parents cannot be obliged to do much of anything to protect its welfare. The problem with this argument, of course, is that it is not the interests of the fetus that trigger parental duties, but the interests of the child it will become. It is the avoidance of harm or impairment to that child that may give parents a duty to intervene prenatally. But to claim that the child's interests create duties before he is born is not to claim that those duties are as strong as the duties that would be owed him to prevent the same harms or confer the same benefits after he was born.

Plausible claims for lesser prenatal duties have been offered. The most familiar is the claim that the duties owed to the child before it is born are limited by the mother's right to control her own body and may be outweighed by the impositions on her that are required for their fulfilment. Unlike a medication given to a child, a medication given to a fetus to protect the health of the child must be administered to, or through, the woman carrying the child. Her right to control her own body may condition, morally and legally, her duty to prevent harm or impairment to the fetus she is carrying. This claim is hard to dispute, but its moral (as opposed to its legal) weight can be exaggerated: as Tom Murray points out (1996), the impositions on a pregnant woman's body required to prevent harm or impairment to the child she intends to bear may be a good deal less onerous than the

<sup>7</sup> We thus respectfully disagree with Scully's suggestion (2008, ch. 4) that deaf parents may have special reasons to refrain from correcting deafness in their fetuses. We have argued against the belief that impairments or the lack of impairments are particularly important affinities in the parent-child relationship (Asch and Wasserman, 2005). More broadly, the considerations we have raised about prenatal therapy apply to disabled as well as non-disabled parents.

sacrifices required of parents to prevent harm or impairments to their born children. If a father is expected to give up bone marrow, or a kidney, for his child, it does not seem unreasonable to expect a pregnant woman to take folic acid supplements or to abstain from drinking alcohol. It does not seem morally relevant that her actions or omissions have a more direct impact on her child's health than any actions she could take after his birth.<sup>8</sup>

## Trade-offs within a family

Though none of the arguments we have reviewed would support a categorical difference in the duties owed by parents to born and unborn children, we can assume that their duties to the latter are slightly weaker than the former. We can also assume that parents have stronger duties to prevent or avoid causing harm to their children than to secure or preserve benefits for them – although making comparisons between the harms and benefits in question is clearly difficult. If it can be acceptable for parents to impose a substantial risk of serious harms on their born children, it can also be acceptable for them to impose on their unborn children a significant risk of not obtaining important benefits.

Thus, for example, we accord parents great moral and legal latitude regarding where they choose to raise their children, even when that choice results in significant increases in the risk of physical harm or impairment to those children. Murray (1996) offers the case of a father who can escape unemployment, bankruptcy and foreclosure in a West Texas town by taking a secure job with good benefits in the 'cancer corridor' of the Houston shipping channel. He has a wife and an unborn child, whose prospects will in many respects be far brighter in their new environment but who will face grave if lower-probability health threats. Murray holds, and we think most readers would agree, that the 'all-things-considered' decision to move would be 'eminently sensible', even if others in similar circumstances might have weighed the risks and benefits differently and decided to stay put.

It might be thought that the acceptability of risks to the unborn child in Murray's case depends on their very low odds of materializing; after all, even in American cancer corridors, most people do not get sick. Imagine, then, another decision about a family move, where the prospect of harm, albeit of slightly lesser magnitude, is much greater. Consider parents with two children, one of whom is starting to develop severe asthma. His condition would be significantly mitigated, if not prevented, by the dry air of the American Southwest. The parents can both get jobs in Phoenix, but they and their children are deeply rooted in Boston – their family is almost entirely in the Boston area, as are most of their close friends; the children go to superb schools without equal in Phoenix; and they are active members of

<sup>8</sup> Others argue for additional differences. Kamm (1992), for example, holds that children have a weaker claim to certain goods that can be taken from them prenatally than they have to those same goods if they can only be deprived of them after birth. The fetus lacks the property rights of a child, so taking away certain goods from the fetus may be acceptable even if taking away those same goods from a born child, with the same effect on that child, would not be. For example, she argues that an individual has no claim as a fetus to the genes that contribute to high intelligence. A mother might permissibly take those genes from the fetus, thereby depriving the future child of 'surplus' intelligence, in order to help an existing child. But she would be wrong to deprive an existing child of those resources to help another. Kamm does not find the same prenatal and postnatal difference for harms, however – among which she would count the lack of normal intelligence. It would be as wrong for a mother to deprive her child of the genetic or neural basis for normal intelligence before or after birth. It is not clear whether Kamm would make the same claim with respect to omissions as actions – that it would be wrong for the mother to refuse to take a pill that would prevent the fetus her child would become from developing normal intelligence, at least if the pill had no significant side effects on mother or child.



a synagogue and many social groups. Still, it might be in the interests of the child with asthma, considered alone, to move, given the priority that some philosophers would accord to the 'worst off'. But it is not clear that the family would be obliged to accord such priority to this child's interests, although they surely would be required to take costly and inconvenient measures to prevent or treat his asthma in the Boston area. If the parents are not required to make the move, they could hardly be required to make a move with similar costs on behalf of an unborn child, so that he could enter the only existing prenatal gene replacement program for genes associated with respiratory illnesses.

## The priority of avoiding harm and trade-offs among the interests of the unborn child

In assessing the moral urgency of correcting a static impairment, we find little use for the familiar distinction between therapy and enhancement. We do not deny that the correction of impairments can be seen as therapy rather than enhancement; rather, we deny the moral significance of the distinction. Impairments will involve capacities or functions below a species-typical or biological norm, and so their correction to within the normal range will count as therapy. Achieving normal functioning may be associated with avoiding non-comparative harms, such as stigmatization or chronic pain; to the extent it is, it will have greater moral urgency. But not all impairments are associated with such harms, and their correction will have less urgency if they are not. Moreover, it may sometimes be the case that a child must exceed normal function to avoid non-comparative harms. A child's odds of survival in a dangerous or toxic environment may be greatly improved by raising various capacities well above the species norm. Regarding prenatal interventions to increase such capacities as therapeutic would be a stretch, but they might well have a greater moral urgency than interventions to raise impaired capacities to a normal level in a more hospitable environment.

Second, although it is hard to express precisely, prospective parents should give greater priority to avoiding many or most significant harms to their future child than to preventing or correcting many or most of their static impairments. Parents should be willing to make greater sacrifices to protect their future children from severe harms than to endow them with greater capacities. Because severe depression would arguably qualify as a non-comparative harm, a pregnant woman might have a stronger duty to subject herself to an onerous drug regimen to prevent her child from living with severe and unrelieved depression than to prevent him from being born blind or deaf. Of course, much will depend on the magnitude of the harms to be avoided and the benefits to be secured, despite the difficulty of precise comparisons. A pregnant woman might well be expected to do more to prevent her child from being born blind than to prevent him from having an occasional migraine.

We might even recognize a presumption against exposing future children to exceptional harms to confer exceptional benefits. Thus, to take a fanciful example of gene transfer (and all such examples are fanciful at this stage), it would be difficult to justify the replacement of a gene associated with both severe visual impairments and deep psychological equanimity, with a gene associated with remarkable visual acuity but severe depression or shortened life-expectancy. A much less fanciful example is suggested by a recent study linking folic acid consumption by pregnant women with respiratory illness to the fetuses they sought to protect from neural tube defects. A pregnant woman might reasonably decline to take folic

acid if the supplement would significantly increase the risk that her child would suffer painful or life-shortening respiratory diseases, even if taking the drug significantly reduced the risk that he would have spina bifida.

We are well aware that our case against treating static impairments as non-comparative harms may seem like special pleading. We cannot reject the possibility that plausible arguments will be made that other alleged harms, such as depression or reduced longevity, do not warrant that status, either, or that the category itself is ultimately empty or useless. But whether it is seen in terms of preventing harms to future children or in terms of conferring benefits on them, the duty of prospective parents to intervene prenatally is not straightforward. Its content and strength depend on contested appraisals of the impact of acting or failing to act on lives that are not yet in being, and it will be conditioned by the myriad of other duties and prerogatives of the prospective parents.

Finally, we should not delude ourselves into thinking that prenatal modifications will ever eliminate disability. Families and communities will always include members who are born with or acquire significant impairments. It would be foolish to imagine that prenatal therapy, any more than prenatal and preconception testing, will allow us to escape the challenges of inclusion.<sup>9</sup>

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<sup>9</sup> We would like to thank Shira Roszler and Daniel Putnam for valuable assistance with this chapter. Although we developed our account of prenatal therapy without reference to Scully’s and Shakespeare’s recent writing on the subject, we believe that our views are broadly compatible with theirs (Shakespeare, 2006, ch. 8; Scully, 2008, ch. 8).

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