Exploring Bioethics
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Introduction

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As you read through this FreeBook, you will notice that some excerpts reference previous chapters – please note that these are references to the original text and not the Freebook.
A Chip Off the Old Block: The Ethics of Shaping Children to be Like Their Parents
01:: A Chip Off the Old Block: The Ethics of Shaping Children to be Like Their Parents

Introduction

I am proud of all of my children’s accomplishments, but two recent accomplishments by my oldest child made me especially proud: The first 5K run she and I did together (as part of a wonderful program called “Girls on the Run”), and when she passed her first belt test in the karate school where I train. In both cases, my daughter was following in my own footsteps, pursuing activities that I pursue and value. I was also proud of her when she did a solo in the church choir, but since I’m neither religious nor musical, this achievement didn’t have the same “icing on the cake” for me. There is something especially stirring about seeing one’s child following in one’s footsteps, knowing that she is “a chip off the old block.”

But for some parents, the child’s traveling down the parent’s path isn’t just icing on the cake: it is the cake. Some parents don’t just hope that their children will be chips off the old block; they rather insist on it, and they feel that they have a right to do so. Perhaps most often, this insistence is manifested in parental attempts to ensure that children adopt the parents’ religion, value system, or worldview—what Rawls would call their “comprehensive doctrines.” But parents often try to shape other things about their children to make them more like their parents. Parents with a love of and ability to create music might seek to instill that same love and ability in their children. Families with traditions of attachment to certain careers might push their children to become doctors or lawyers or soldiers just like their parents and grandparents before them. Small business owners and farmers often expect to turn those enterprises over to their children who will tend to them in their turn. The legitimacy of such practices is commonly taken for granted as part of what many parents assume is their right to raise their children however they see fit, subject only to minimal requirements that they avoid abusing or neglecting them.

In some cases, parental efforts to shape their children are motivated not only by the desire that their children be like them, but also by the desire to perpetuate the parent’s values, culture, religion, and way of life. Indeed, sometimes the very survival of these things depends on children following in their parents’ footsteps. This fact may seem to the parents to provide additional justification for shaping their children. The much-discussed case of the Old Order Amish comes to mind here. Typically, the Amish limit their children’s formal schooling to the 8th grade, and whenever possible, they conduct that schooling in local schools run by the Amish themselves. After the 8th grade, Amish children typically learn a traditional Amish trade through an apprenticeship system. This system effectively prepares children for an Amish career and way of life. But it also creates significant hurdles for pursuing careers other than farm work or a limited number of skilled trades, and thus for leading prosperous lives in contemporary non-Amish society.
The Amish seek to lock their children into their lifestyle by manipulating the social and educational environment in which the child develops—what we might call the “environmental shaping” of children. Recently, it has become possible to shape children more directly, by manipulating their genetic makeup. Consider Sharon Duchesneau and Candy McCullough, a Deaf couple who wanted children, and preferred that they be deaf, just like their parents. They decided to employ in vitro fertilization and selected a man with five generations of deafness in his family to serve as a gamete donor. Their motivation appears to have included both the desire that their child be like them, and the desire to help perpetuate their own Deaf culture into the next generation. Their decision raises worries similar to those raised in the case of the Amish children: While it facilitated their children’s entry into Deaf culture, it also raised significant hurdles for life outside that culture. In this way, the Duchesneau-McCullough children’s intentionally selected deafness is rather like the lack of education beyond the 8th grade, in that it creates an obstacle for the children if they decide that they do not want to be chips off the old block.

Duchesneau and McCullough used a fairly low-tech form of genetic shaping. More complicated methods—some available already, and others on their way—will allow parents to engage in ever more fine-grained genetic shaping. It is already possible to use pre-implantation genetic diagnosis to select for implantation only those embryos that possess certain genes. Dena Davis reports that this technique has been used by parents with achondroplasia (a form of dwarfism) to ensure that their children will share this condition. In the near future, it will probably be possible to engage in more direct genetic engineering of children, by replacing small numbers of genes in an early-stage embryo, for example. In the farther future, it may become possible to create a baby with a genome made more or less to order, or perhaps even to create the ultimate chip off the old block: a human clone.

Genetic shaping has often been analyzed in the context of debates about the permissibility of creating “enhanced” children. But as we have just seen, parents might employ genetic shaping methods not to create super-children, but to create children that are simply more like their parents, and more likely to follow in their parents’ footsteps. The most obvious way to do this, of course, would be to use genetic shaping to increase the number of genetically influenced traits the child has in common with the parent. But parents might employ genetic methods indirectly to do the kind of shaping now done primarily through education and other environmental methods. Although genetic methods may not be able to directly influence a child’s choices and values, they might be used to grease the wheels by ensuring that their children are good matches for paths that the parents value, and to erect barriers to competing paths. Parents with sexist worldviews might use genetic shaping to decrease their daughters’ intelligence and ambition; intellectual parents might seek to increase their
children’s intelligence while decreasing traits that might make them good at athletic endeavors that could distract them from the life of the mind.

**Yoder, Feinberg, and the Open Future**

Philosophical thinking about the parent’s rights to engage in environmental shaping has been heavily influenced by the case of *Wisconsin v. Yoder*, and Joel Feinberg’s discussion of it in his article, “The Child’s Right to an Open Future.” Feinberg’s central claim is that a child has a right to an open future, that is, a right not to have important decisions made for her simply because she cannot make them yet on her own. Although this idea seems simple enough, it admits of two rather different interpretations, and Feinberg seems at various times to endorse each. In some passages, Feinberg seems to endorse the right of children to “be permitted to reach maturity with *as many* open options, opportunities, and advantages *as possible*.” This suggests a right to a *maximally open* future, with parents making no more decisions for children than absolutely necessary. In other passages, Feinberg seems to suggest a more moderate view, writing that the Amish parents “are permitted and indeed expected to make every reasonable effort to transmit by example and precept their own values to their children,” which certainly suggests that parents are allowed to try to shape their children’s values. Indeed, he writes that, so long as the parent does not try to insulate the child from outside influences that may be contrary to the parent’s values, the parent “is free to provide any kind of religious upbringing he chooses, or none at all, . . . to attempt to transmit his own ideals, moral and political, whatever they may be, to his child; in short, to create whatever environment of influences he can for his child, subject to the state’s important but minimal standards of humanity, health, and education.”

Perhaps the closest thing to a recent philosophical defense of the maximal openness interpretation of the right to an open future appears in work by Matthew Clayton. Clayton argues, provocatively, that it is wrong for parents to have their infant children baptized, since this “enrolls” them into their parents’ comprehensive doctrine. Such “enrollment,” he claims, violates their right to choose their own comprehensive doctrines when they are old enough. Moreover, he suggests that even taking a child to church may wrong the child, if it causes her to adopt a comprehensive doctrine that it may later be distressing for her to shed. Clayton’s argument is based on an analogy between the state and the parents: In both cases, he argues, a coercive authority operates, and to avoid infringing on the rights of its subjects, it must remain neutral on the question of what comprehensive doctrine its subjects should adopt.

In the abstract, at least, the arguments for the maximal openness interpretation of the child’s right to an open future seem compelling. I have no right to shape your values, or decide what church you shall attend. Nor do I have the right to make a decision about your future simply because you are unable to make it right now. For
instance, if it’s 3:00 a.m. and you are asleep, I can’t just “volunteer” you for a burdensome committee assignment simply because your unconsciousness temporarily precludes you from deciding for yourself. Since my children are persons, and since they will (if all goes well) develop autonomy, what right do I have to decide what values they shall hold or what church they shall attend, or to make any other decisions that will constrain their future choices? Of course, it may be necessary for their well-being or the future development of their autonomy for me to make some decisions for my children. So perhaps it’s fine for me to decide on their behalf that they will brush their teeth, eat vegetables, and learn their multiplication tables. (By analogy, it is often permissible to make decisions on behalf of an incapacitated adult where those decisions are necessary to preserving that person’s life or well-being.) But why shouldn’t I be required to avoid making any more decisions for them than absolutely necessary? Why shouldn’t I be required to bring them into adulthood with as many options—as maximally open a future—as I can give them?

Despite the logical appeal of this argument, it is not widely accepted, even among liberal theorists who take children’s rights seriously. It is not difficult to understand why. After all, the maximal openness interpretation of the child’s right to an open future would impose serious obstacles to many parents’ ability to live according to their own comprehensive doctrines. Taken at face value, the maximal openness interpretation would appear to forbid parents from taking their young children to Sunday School, for fear that they may unjustly instill values and religious views that they may find it difficult or traumatic to give up later. We can easily imagine religious parents—even if they are good liberals—retorting that “It’s not brainwashing, it’s just Sunday School!” Having to choose between skipping church or hiring a babysitter so that one can insulate one’s children from one’s own religious observances would seem to be a rather large imposition on the parent’s religious rights. A separation of church and state is fine, but the idea that parents must erect a wall separating their religious life from their children seems far-fetched. Of course, such a view would not only apply to religious views and values, but to any value or decision that an autonomous person has the right to make for herself. Perhaps I should worry that encouraging my children to prepare for college illegitimately biases them against the skilled trades. Or perhaps I should worry that my family’s “girls can do anything boys can do” mantra unfairly biases my children against adopting more traditional gender roles later in life. Perhaps I should worry that, rather than celebrating my daughter’s decision to do Girls on the Run again, I should encourage her to take ballet lessons instead, so as to keep her options more open. Most parents—myself included—would find such suggestions to be implausibly radical.

Not surprisingly, most liberal theorists who take children’s rights seriously have sought a middle ground between countenancing extreme efforts to shape children on
the one hand, and the maximal openness interpretation of the child's right to an open future on the other. This moderate interpretation of the child's right to an open future asserts that it is legitimate for parents to bring up their child in the parent's own comprehensive doctrines, so long as (1) they do not try to "lock in" that comprehensive doctrine so that the child is unable to question or reject it later, (2) they foster (or allow schools to foster) critical thinking capacities sufficient for the child eventually to reflect on their parents' comprehensive doctrine, and (3) they do not work to deprive the child of other options or the knowledge of them.

Of course, the fact that the moderate interpretation of the child's right to an open future is a better fit with our intuitions and practices is not, in itself a decisive argument for it. Moreover, the argument for the maximal openness interpretation remains quite compelling, at least in the abstract. Given the presumption that infringements to autonomy must be both justified and as minimal as possible even when they are justified, what reason could there be for not giving children the most open futures possible?

One reason might involve the rights of the parents, and in particular the parents' right to autonomy. Indeed, the reason why most parents would chafe under the requirement to provide maximally open futures for their children is that such a requirement would appear to constrain their own autonomy. Certainly parents have the right to live according to their own values, beliefs, and life plans, and, one might think, they have a right to some say in how they raise their children. So we might think that parents have the right to decide, for example, that they will raise Christian or Muslim or Agnostic families because doing so is part and parcel of their own commitments to those worldviews. This is certainly the reasoning behind the Supreme Court's decision in *Yoder*: The majority determined that the parent's own rights to freely exercise their Amish religion included the right to raise their children in that religion.

Of course, the parents' rights to direct their children's upbringing are not absolute. As Justice Rutledge wrote in the 1944 case, *Prince v. Massachusetts*, "Parents may be free to become martyrs themselves. But it does not follow [that] they are free, in identical circumstances, to make martyrs of their children before they have reached the age of full and legal discretion when they can make that choice for themselves." Whatever autonomy-based rights parents may have to shape their children are limited by the child's own rights, including the rights to make decisions for themselves when they are able.

Hence, it is very tempting to see parents as having autonomy-based rights to direct their children's upbringing—to shape them, in other words—but to see those rights as being constrained by the child's own rights, including and especially the right to an open future. But on the flipside, it is tempting to see the parental autonomy rights as the reason why the child's right to an open future does not require parents to
provide a *maximally* open future. This suggests a very appealing picture in which the right answer about how much a parent is allowed to shape a child is determined by a balancing or equilibrium of two opposing rights. On the one hand, parents clearly have the right to live according to their own comprehensive doctrines, and this right may be thought to include or imply a right to raise their children within those comprehensive doctrines. But these rights do not seem to be absolute. And one explanation for why they are not absolute is that they are limited by the child’s right to an open future. We might think, then, of the moderate interpretation of the right to an open future as the outcome of an equilibrium or balance between competing rights. In other words, we might think of the child’s right to an open future, *taken in isolation*, as being maximally expansive. But in practice, it is limited by the countervailing weight of the parent’s rights to live their own lives. By the same token, we might think of the parent’s right to live her own life, *taken in isolation*, as being maximally expansive. But in practice, this right is limited by the countervailing weight of the child’s rights, including the right to an open future.

It is important to emphasize that on the balancing model, each right would be expansive but for the countervailing moral force from the other: The child’s right to an open future *would* require parents to provide a *maximally* open future, but for the countervailing moral force of the parent’s autonomy rights. The parent’s autonomy rights *would* permit extreme parental shaping (e.g., of the kind practiced by the Amish), *but* for the countervailing moral force of the child’s right to an open future. Notice that this is how we often think of liberty rights: The old saw that my right to swing my arm ends where your nose begins implies that, taken in isolation (your nose being absent from the picture), my right to swing my arm is maximally expansive. But once your nose enters the picture, the countervailing moral force of your right not to have it hit limits my right to swing.

So the balancing model taps into a very natural way to think about how rights interact, and in so doing it provides a blueprint for generating the moderate view about parental shaping: The child’s right to an open future makes it immoral for the parent to try to lock in her comprehensive doctrine, while the parent’s autonomy rights prevent the child’s right to an open future from requiring parents to provide the child with a maximally open future.

I believe that this balancing model is implicit in much of our thinking about parental rights. The majority of the Justices in *Yoder* are clearly balancing the parents’ free exercise and other autonomy rights against the rights of the children (primarily their right to a decent education). Much of the commentary on *Yoder* seems to take this balancing model for granted, and simply quibbles about whether the court got the balance right or balanced the right things (some commentators fault the court for not including the children’s free exercise rights in the balance).
But the balancing rights model is not confined to discussions of legal cases like Yoder. For example, William Galston, writing about “...the desire of parents to pass on their way of life to their children,” notes that “few parents ... are ... immune from the force of this desire. What could be more natural? ... Still, your child is at once a future adult and a future citizen. Your authority as a parent is limited by both these facts.” Similarly, Colin Macleod discusses a parental “prerogative of provisionally privileging the conception of the good that they favor.” This “prerogative” appears to result from the interplay of two moral considerations: “the parental interest in having children share a familiar commitment to a common conception of the good,” and the child’s interest in acquiring autonomy. Hence, Macleod writes, “the exercise of parental autonomy is constrained by the requirement that children be afforded free and full access to the deliberative resources available in the pluralistic public culture.” It is natural to read his derivation of “constrained parental autonomy” as arising from a balance between parents’ morally protected interest in having their children share their comprehensive doctrine and the child’s morally protected interest in developing the capacity for self-determination.

Despite its appeal as a way to justify intuitively plausible limits to both the child’s right to an open future and the parent’s right to direct the child’s upbringing, I think that we should reject the balancing model. Here’s why: For all its intuitive appeal in cases of environmental shaping, the balancing rights model has unsettling consequences when applied to certain kinds of genetic shaping.

**Open Futures and the Non-Identity Problem**

As we noted earlier, it is tempting to criticize Duchesneau and McCullough for trying to lock their children into the Deaf community, much as many of us would criticize the Amish for trying to lock their children into the Amish community. Yet there is a serious obstacle to making that charge stick—an obstacle that arises from what has come to be called the non-identity problem.

The non-identity problem arises because certain methods of genetic shaping have the following curious property: Had the child not been shaped a certain way, that child would not exist. The methods used by Duchesneau and McCullough to ensure that their child would be deaf have this property: had they not selected the sperm donor they did, then that particular child would not exist. Some other child might have existed, but that child would not have been the same child as the one who did come into existence, since this other child would have been created from at least one different gamete. This being the case, it is difficult to make what would otherwise seem like a natural claim, viz., that his mothers’ procreative decision harmed him (either by making him deaf or by closing off his options). So long as his life is worth living—as it surely is—it seems as though he has not been harmed, since the only alternative to his
being born deaf was his not being born at all. The non-identity problem arises in any situation—call it a “non-identity situation”—where the conditions necessary to a person’s creation unavoidably cause that person to have a condition that we would normally count as an impairment. For our purposes, we can think of a constrained future as a form of impairment, relative to a more open future. The non-identity problem seems to block the claim that Duchesneau and McCullough did anything wrong in shaping their children to be deaf, for had they not done so, these particular children would not even exist.

Like most philosophical problems, the non-identity problem does not so much suffer from the lack of a solution as from multiple solutions, each of which requires us to give up some claim that seems intuitively plausible. These solutions fall into three main categories: (1) biting the bullet by claiming that it cannot be wrong to deliberately create an impaired child in a non-identity situation, so long as the child’s life is worth living; (2) claiming that, contrary to appearances, the child is harmed or has her rights violated; and (3) claiming that a procreative act undertaken in a non-identity situation can be wrong even though it neither harms nor violates the rights of the resulting child.

According to the bullet-biting approach, a child born in a non-identity situation can only be harmed if her impairments make her life not worth living. Otherwise, she cannot be said to be harmed, since the only available alternative to being born in the impaired condition was not being born at all. But if the child has not been harmed by the process on which her very existence depends, then how can she have any legitimate moral complaint against her parents for undergoing that process? And if the child has no legitimate moral complaint against her parents, then how can the parents be said to have acted wrongly? According to the bullet-biting view, so long as the child’s life is worth living, she has no basis to complain about interventions on which her very existence depends, and consequently, the parents do not act wrongly in employing those interventions. On this view, shaping a child, even in ways that drastically narrow her future options, cannot be wrong if that child’s existence depends on having been shaped that way, and if her life with its narrowed options is still better than no life at all.

This approach to the non-identity problem appeals to those who favor “genetic libertarianism,” according to which parents have vast moral freedom to shape their children however they wish. However, it suffers from serious counter-examples. Consider the Gammas in Aldous Huxley’s Brave New World. The Gammas are humans who are only capable of doing menial tasks, but who are happy to do them. Imagine that Gamma-like children are created by pre-implantation genetic selection (perhaps by Gamma-like parents who want their own children to be chips off the old block): Embryos are tested for the genes for various Gamma-like traits, and only those embryos
with genetic profiles that will result in Gamma-like children are selected for implantation. Thus, for the resulting Gamma-like child, the following will be true: The only way the parents could have avoided creating a Gamma-like child would have been to avoid creating that particular child at all, since they would have had to choose a different embryo to implant. This being the case, on the bullet-biting view, so long as her life is still worth living, she has not been harmed, and so she has no basis to complain about her parents’ decision, and so the parents did nothing wrong. So, on the bullet-biting view, we must deny the common sense intuition that it would be wrong to employ a technique like pre-implantation genetic selection to create a Gamma-like child. That’s a hard bullet to bite.

Those of us who are unwilling to bite the bullet have two remaining options: Claiming that genetic shaping in non-identity situations, can, contrary to appearances, harm or violate the rights of the child, or claiming that genetic shaping in non-identity situations can be wrong even if it does not harm or violate the rights of the child.

There have been attempts to show that, despite appearances, the child in non-identity cases really is harmed. Such attempts typically begin with the observation that the non-identity problem gets much of its initial bite from the assumption that harm must always be comparative: An action harms me only if I would have been better off had that action not been done. Once we adopt this conception of harm, we seem forced into the non-identity problem, since it is difficult to see how I can be harmed by something without which my worth-living life would not have been possible. However, some philosophers have argued that this is not the only coherent conception of harm. For example, one might claim that certain conditions are harms just in case they are the sorts of things that impair normal functioning, create suffering, significantly narrow one’s life choices, etc.

But even if we can coherently speak of the child in a non-identity situation being harmed, the fact that the harm was necessary to the child’s very existence makes it plausible to regard the child’s assessment that her life is still worth living as a sort of retroactive consent to the harm. In other words, it is plausible to assume that a child will give her consent to whatever harms are necessary for her to exist, assuming that she regards her existence even in the harmed condition as being preferable to non-existence.

This same problem befalls proposals to claim that bringing an impaired child into existence in a non-identity situation violates that child’s rights. Even if genetically shaping a child in a non-identity situation violates her right to an open future, given that the only available alternative to her condition is non-existence, she can be reasonably expected to waive the right to the open future that she never could have had anyway. Since it is generally thought to be permissible to do a thing that would otherwise violate a right if the right-holder waives the right, it would appear that
genetic shaping in non-identity situations would be permissible even if it results in a child with a less than satisfactorily open future.

Although some philosophers continue to seek solutions to the non-identity problem that salvage the idea that creating an impaired child in a non-identity situation somehow wrongs the child, the prospects for such a solution look pretty grim. If we are unwilling to bite the bullet, that leaves the third approach, namely conceding that the child is neither harmed nor the victim of a rights violation, but nevertheless maintaining that his parents have acted wrongly.

How would that position work? One influential account is given by Joel Feinberg. Feinberg imagines a child born with a withered arm, whose mother “had only two options with respect to his birth. One was to do what she did, which led to his being born with the withered arm. The other . . . would have led to his never having existed at all, which even the child acknowledges was the worse fate.” Feinberg concedes that “I do not think the child can establish a grievance against her so long as he concedes that his handicapped existence is far preferable to no existence at all. For if he were to claim that she wronged him by doing what she did, that would commit him to the judgment that her duty to him had been to refrain from doing what she did; but if she had refrained, that would have led to his never having been born, an even worse result from his point of view.” Feinberg concludes that “There is no doubt that the mother did act wrongly, but it does not follow that her wrongdoing wronged any particular person, or had any particular victim. She must be blamed for wantonly introducing a certain evil into the world, not for harming, or for violating the rights of, a person.”

So long as we are clear that the “certain evil” is the impairment rather than the person who has it, Feinberg’s point seems appealing. Applied to the kinds of cases at issue here, Feinberg’s reasoning suggests that creating a child with a less than satisfactorily open future in a non-identity situation is wrong, but not because it violates the child’s rights. Instead, it is what Feinberg calls a non-grievance wrong, something that is wrong even though it does not do anything wrong to any person. Since no one has a legitimate grievance against the wrongdoer, the wrong is, in effect, victimless. This idea of a non-grievance or victimless wrong is certainly an odd idea, given how natural it is to think that every wrong thing must be a wrong thing that is done to someone who is its victim. However, given the problems with the claim that a child can be victimized by an action that was a causally necessary condition of her very existence, and the unpalatability of biting the bullet, this victimless wrongdoing approach seems like the least bad solution to the non-identity problem.

Balancing Rights and the Non-Identity Problem

So far, so good. Except for this: If genetic shaping in non-identity situations does not
violate anyone’s rights because it is a victimless or non-grievance wrongdoing, then we will have difficulty maintaining that extreme genetic shaping is immoral if we adopt the competing rights model of the moral status of non-genetic shaping discussed earlier.

The problem is that a victimless or non-grievance wrong seems too insubstantial to counterbalance the moral clout of a parents’ autonomy-based rights. This kind of worry has been given explicit voice in a slightly different context by John Robertson: “If ART [assisted reproductive technologies—rn] harmed offspring, a strong case for limiting them might exist. But if due to the non-identity problem harm to offspring is questionable or non-existent, then harm to offspring in those cases cannot justify limiting use of ARTs. This is particularly true in those cases in which use of the ART implicates the procreative liberty of infertile couples and others who use them.”

A similar worry applies to cases of genetic shaping. If we rely on the child’s right to an open future to provide a counterweight that prevents parental autonomy rights from expanding to permit extreme shaping, then we encounter a serious problem in situations where parents employ genetic shaping methods in non-identity situations. Because we can expect the child to waive her right to an open future when having her future narrowed is an unavoidable part of her coming into existence, that right becomes unavailable to provide any counterweight to the parents’ autonomy rights. Without the countervailing moral force of the right to an open future, the parents’ autonomy rights expand to permit far more extensive genetic shaping than most of us think is permissible. In fact, with the right to an open future out of the way, parents would become more free to employ genetic shaping methods than they are to employ environmental shaping methods. For those of us who have the same qualms about unconstrained shaping of either sort, this is an unwelcome conclusion. It is even more unwelcome for those who think that genetic shaping is more problematic than environmental shaping.

One might wonder why the parental rights would remain unconstrained in a non-identity situation; after all, we have argued that creating a child in an impaired condition can still be wrong, even if the wrong is a victimless wrong. The reason, as Robertson notes, is that a mere victimless wrong seems insufficiently robust to outweigh the parents’ autonomy rights. A right, after all, is not easily outweighed (otherwise it would not be a right). Hence, it is hard to see how a mere free-floating, impersonal, victimless wrongdoing could outweigh the parents’ autonomy right. Nor does it help to ground the victimless wrongdoing in consequentialist considerations, for example, by claiming that the reason that it is wrong to create a child in an impaired condition in a non-identity situation is that doing so makes the world a less good place than it otherwise could have been. For the point of a right is precisely to insulate agents (at least partially) from considerations of utility. If my right to do X can
be blocked simply because my X-ing makes the world go less well than not X-ing, then I
don’t really have a right to X. Indeed, if we take Mill’s Harm Principle seriously, we
should be disinclined to say that parental autonomy can be infringed for anything less
than harming or violating the rights of another person.

Of course, one might suggest that even though creating a child with a less than
satisfactorily open future in a non-identity situation is a victimless wrong, it is still
sufficiently weighty to provide a counterweight to the parents’ autonomy rights. But
unless we can find a reason to justify treating this victimless wrongdoing as being as
morally weighty as a harm or a rights violation to another person, such a claim seems
ad hoc. Even if the reasons generated by a victimless wrongdoing have some weight, it
is difficult to see why they would have enough weight to provide anything comparable
to the counterweight otherwise provided by the child’s right to an open future. To see
why, we must go back to the balancing model. Recall that the balancing model involves
positing a parental right that creates countervailing moral force sufficient to keep the
child’s right to an open future from becoming maximally expansive. In order to do that,
the parent’s autonomy rights must be very weighty indeed—weighty enough to
significantly constrain rights held by the child that protect her future autonomy. But
unless the wrongness of this victimless wrongdoing is grounded in something as
weighty as the child’s right to an open future, then when the child’s right ceases to
operate (as it does in the non-identity situation), it will not be able to produce as much
moral counterweight as the child’s right would have provided. Normally, if I have a right
to do X, then the only thing that can override my right in a particular situation (and
thus make it immoral for me to X in that situation) is the fact that my X-ing will harm
someone or violate someone’s rights. But if we accept the “victimless wrongdoing”
approach to the non-identity problem, then any right that the parent has to shape her
child cannot be overridden, since the shaping neither harms nor violates the rights of
the child so created.

To summarize: If we adopt the opposing rights view for environmental shaping,
we will face a serious problem when we move to cases that involve genetic shaping in
non-identity situations—at least if we take what seems like the most promising
approach to the non-identity problem that treats the wrong done as a victimless wrong
that does not violate the rights of the child. For in non-identity cases, the child’s right
to an open future is likely to be waived, so that it can no longer operate as a
counterweight to limit the application of the parents’ autonomy rights. Lacking this
moral counterweight, the parents’ autonomy rights would become maximally expansive,
in much the same way that my right to swing my arm becomes maximally expansive
once your nose is out of the way. These now expansive parental autonomy rights would
then seem to permit very extreme forms of genetic shaping. Consequently, if we are to
avoid having the non-identity problem block our moral criticism of extreme genetic
shaping, then we must either find an alternative to the non-complaint solution to the non-identity problem, or we must avoid the model of parental authority that sees it as a balance between an otherwise expansive parental authority and an otherwise expansive child’s right to an open future. I am skeptical of finding an alternative to the non-complaint approach to the non-identity problem. I am more hopeful about the prospects for basing a moderate view of the limits of permissible parental shaping on something other than the balancing model.

**Denying a Parental Right to Shape**

To avoid having the moderate position on the right to an open future unravel when we encounter non-identity situations, we must abandon the balancing model and find another way to avoid both the maximal openness interpretation of the right to an open future and the claim that parents have almost unlimited authority to shape their children however they wish. Fortunately, recent philosophical work on children’s rights provides resources that may allow us to do this. Several philosophers have recently argued that parents may legitimately engage in many behaviors that shape their children in ways incompatible with the maximal openness interpretation of the right to an open future, but without basing these arguments on a parent’s free-standing moral right to shape their children.

Before examining these arguments, it is important to distinguish two very different ways to justify a limited parental prerogative to shape their children. One is to derive that prerogative from a right that protects (and thus gives moral weight to) the parent’s interest in shaping their children. For example, such a right would justify enrolling a child in Sunday School, or Girls on the Run, or Boy Scouts, in terms of the parent’s interest in helping to direct the child’s developing interests and values. By contrast, we could think that such things are permissible (if they are) because they are in the interests of the child. In this way, we might attempt to derive limited parental prerogatives to shape their children not from the parents’ interests, but from the child’s interests.

The idea that a parental right might actually derive from the child’s interest is hardly new. The idea that parental rights are like fiduciary or stewardship rights, which has been extremely influential in recent work on children, has precisely this feature. The idea is to model parental rights on the rights of a steward or fiduciary agent, so that in both cases, the right exists only to enable one person to protect the interests of some other person. This distinction will be difficult to track if we use the same term to refer both to rights that protect the right-holder’s interests and to rights that protect some other person’s interests. Consequently, I will use the term “prerogative” to refer to a parent’s moral permission that derives from the child’s interests, and I will use the term “right” to refer to parental rights that protect the parents’ own interests.
Now, if we can derive a limited parental prerogative to shape one's children from the child's interests rather than from the parents' autonomy rights, then we might avoid the balancing model that unravels when we encounter the non-identity problem. For if we don’t need to appeal to a free-standing parental right to shape to prevent the right to an open future from becoming maximally expansive, then we need not worry about the parental right to shape becoming maximally expansive in non-identity situations where the right to an open future is inoperative.

This assumes, however, that we can find a way to ground a limited parental prerogative to shape their children in the interests of the child. (Otherwise, we risk the opposite problem—namely that the child’s right to an open future will, lacking anything to counterbalance it, expand so as to require parents to provide a maximally open future.) Fortunately, recent work in the ethics of parents and children provides some hope of finding considerations that would justify limited parental shaping, not because it serves the parents’ interest in shaping, but because it serves the child’s own interests.

To see how this suggestion might work, let’s begin with an insightful paper by Claudia Mills, who argues that “it is both impossible and undesirable to try to provide children with an ‘open’ future in any meaningful sense.” It is impossible, she argues, because it is impossible for parents to be strictly neutral among potential options. There is simply no neutral “default” setting that parents can keep switched on, so as to avoid any slight steering of the child one way or another. Mills recounts a friend’s practice of having his son sample a different religion or denomination each week. Although this might seem like a good way to keep the child’s religious options maximally open, Mills predicts that “This little boy is not going to grow up to have any religion at all” because a “weekly survey of various creeds and rituals” does not impart “the experience of belonging to a religion.” Such a “smorgasbord” (as Mills aptly puts it) is very superficial: not only does it provide insufficient time to engage with the complexity of each religion, but it provides insufficient time to learn what it is like to be part of a faith community structured by that religion. But perhaps more importantly, such an approach steers the child to a view of religion as a thing for which to “shop around” rather than something that grounds one’s view of the world, anchors one’s value system, and shapes one’s identity. In attempting to expose the child to many religions, the smorgasbord approach fails to show the child what it is like to have a longstanding commitment to a single religion. Arguably, that is what it really means to have a religion.

Mills argues that similar considerations make it undesirable for parents to try to maximize openness in terms of pursuits, talents, and potential career choices. She argues that having a child hop from sport to sport, musical instrument to musical instrument, and after-school activity to after-school activity, doesn’t provide enough time for the child to meaningfully discover which she most prefers and which she has
most talent for: “Precisely what will be missing from the list is experiences that require time to assimilate and absorb, experiences that are slow and deep, rather than easily scheduled in a escalating spiral of extracurricular activities.” And, one might add, a superficial hopping around approach seems unlikely to help teach one of the most important lessons that such pursuits can teach: the value of persevering through setbacks, practicing on days when you don’t feel like it, and so on. In short, the more we try to maximize openness in our child’s options, the more we fail to give them the experience of being committed to one community or pursuit or value. Instead, we risk imparting a view of life in which commitments are disposable, worldviews are things for which to shop rather than frameworks that ground one’s sense of the world and one’s place within it, and perseverance is unnecessary because if at first you don’t succeed, try a new sport—or get a new religion.

A second and complementary line of thought has been developed by Harry Brighouse and Adam Swift. Although they argue that parents’ interests play a role in justifying the family as an institution, they derive the content of parental rights from the interests of children, claiming that a “parent should have just those rights that it is children’s interests for them to have.” Hence, on their view, parental rights are a form of fiduciary or stewardship rights that protect the child’s interests rather than the parents’ interests. (And thus, for reasons of clarity mentioned above, I’ll refer to them as prerogatives rather than rights.)

What is most distinctive about Brighouse and Swift’s account of the moral prerogatives of parents is their observation that part of what they protect is the child’s vital interest in “relationship goods” provided by the family. Hence, parental prerogatives, in part, make it possible for parents “properly to discharge the parental role on the understanding of that role which ties it to our conception of familial relationship goods.” These relationship goods include the goods intrinsic to childhood as well as the ability to develop capacities needed for fully functioning adulthood, all within a relationship that provides a stable, loving, and nurturing foundation for well-being and healthy psychological development. According to Brighouse and Swift, family relationships that provide these goods “require parents to be free to engage with their children in ways that produce mutual identification and reflect the parents’ judgments about what is valuable in life.” Such relationships involve the sharing of the parent’s self with the child, and since the parent’s self includes his or her values, they involve the parent’s sharing of her values with her child. This, however, will inevitably help to shape the child’s own values: “there can be no value sharing without at least some degree of value shaping.” This is because “a close, loving relationship will surely involve parents’ honestly revealing their enthusiasms and aversions, their sense of what matters in life and what is trivial…. Because people’s values are central to who they are, because successful parenting requires parents to share themselves with their
children, and because value sharing implies at least some degree of value shaping, value shaping is an inherent part of that kind of relationship.”

Hence, according to Brighouse and Swift, some parental shaping of the child’s values is an inevitable by-product of the parent’s sharing of herself with the child—a sharing that is itself in the best interest of the child because it provides vital relationship goods to the child. In light of this, a requirement of maximal openness and parental neutrality turns out not to be in the child’s best interest: “The idea that parents should constantly monitor themselves in their relations with their children in order to screen out anything that might have any influence on their children’s emerging values is ludicrous. It would risk distancing them, creating artifice in the relationship, and depriving their children of the possibility of the warm, spontaneous genuine relationship that they need.”

Although Brighouse and Swift emphasize the legitimacy of shaping that is a by-product of sharing, they also see a role for some legitimate direct and deliberate instilling of their values. Here again, though, they see this as being in the interests of promoting the relationship goods that children need, and they are careful to emphasize that it must not compromise the child’s ability to subject those values to critical reflection when she is older: “When a Christian and cricket-loving parent takes his daughter to a cricket match, or to church, that is not usually an unthinking and automatic sharing of self between parent and child. It is more likely a deliberate decision to introduce the child to an activity, or a worldview, that the parent judges valuable. As long as that kind of deliberate shaping of values is needed for a close relationship between parent and child, and as long as it is done in a way that is consistent with the duty to develop the child’s capacity for autonomy, then, on our account parents have a right to engage in it. . . . The shaping of values is itself, under this aspect, a means to a familial relation of the kind that lies at the heart of our theory.”

A third resource for deriving the legitimacy of some limited parental shaping from the interests of the child rather than the parents comes from the observation that children must be supplied with an initial cognitive-evaluative worldview before they can develop the intellectual skills to reflect on and revise any values or other elements of a comprehensive doctrine. As a number of theorists have noted, without a background or default sense of how the world works and what is good and bad, one cannot organize one’s experience at all, much less develop the critical-thinking skills needed to reflect on the adequacy of that initial default sense. Choices—even choices about whether to retain, revise, or reject a set of values or a worldview—must start from somewhere. One cannot make any choice, autonomous or otherwise, without some values to serve as an evaluative point of reference. Since it is impossible for anyone to choose the values on the basis of which she chooses the values on the basis of which
she chooses the values . . . ad infinitum, it appears that genuine choice requires some initial evaluative starting point, even if that starting point is to be subject to critical evaluation. Since children are best served by having an initial evaluative framework, it seems reasonable to allow parents to offer their frameworks to the child, at least insofar as the parents’ values are morally decent, and at least insofar as the parents refrain from trying to lock in those values.

Similarly, normal cognitive development requires that children have some sort of initial sense of how the world works—a sense that may well include elements of a particular comprehensive doctrine. Moreover, in order for the child to make an eventual decision about religious components of a comprehensive doctrine, she will have to be introduced at some point to the concept of religion itself. How this is done will inevitably nudge the child into one direction or another. As Mills observes, there is no neutral way to do this: Parental affirmations of atheism or even agnosticism privilege certain views about religion no less than parental affirmations of a particular creed. And, far from being the epitome of neutrality, the smorgasbord approach of sampling many different religions carries with it certain attitudes about religion no less than does the announcement to the child that, say, “Mommy and Daddy are Methodists.” Even if we try—as we should—to avoid locking in our religious attitudes in our children, we cannot simply avoid letting them know our views, nor can we avoid the fact that they will probably imitate us, at least for a while.

Finally, it is worth noting that the parents’ free exercise of their own religions and pursuits will, as a matter of course, make certain options more salient, more available, and more appealing to their children than alternatives. A child of Catholic parents will almost inevitably learn more about Eucharist than the Hadj. The fact that I practice karate increases the chance that my children will practice karate, and decreases the chance that they will take up ballet. Partly this is a matter of logistics: It’s easier to pack a kid along to go somewhere you were going anyway. But it’s also part of the fairly natural tendency of children to see what their parents do as worth doing. Children, as it turns out, often want to be chips off the old block. This means that things that parents value are likely to be valued by their children as well, whether that is something as deep as a religion or as inconsequential as a favorite sports team.

Although these considerations vary in the extent to which they apply to every form of shaping, taken together, they suggest that we can develop a plausible liberal, child-respecting account of a limited parental prerogative to shape, and that we can do this without according to parents an independent, free-standing right to shape their children in their own image or according to their own values. On this account, a limited parental prerogative to engage in some activities that will have the effect of shaping the child in their own image or according to their own values derives from the interests of the child rather than the parent. Hence, we do not need to see the limited
prerogative to shape our children as the outcome of a balance between a child’s right to an open future which, left unconstrained, would require a maximally open future, and a free-standing parental right to shape their children. And thus we avoid the problems created by the unraveling of this model when it is confronted with the non-identity problem.

**Conclusion: Blocking Unrestricted Genetic Shaping**

The considerations explored in the previous section suggest that we may be able to defend a moderate interpretation of the child’s right to an open future without positing a free-standing parental right to shape their children, and deploying it to constrain a right to an open future that would otherwise become maximally expansive. Instead, we might derive limited parental prerogatives to shape from the interests of children. This is vital, because in non-identity situations, the child’s right seems not to come into play, so it is unavailable to provide a counterweight to the free-standing parental autonomy right, which would then threaten to become maximally expansive. In this way, the non-identity problem gives those who believe in sharply limited parental rights to shape their children by either environmental or genetic methods a strong reason to derive the limits to the right to an open future from the interests of the child rather than the parent. Hence, it appears that considerations about genetic shaping can provide important reasons to revise how we think about non-genetic shaping. If we believe that there are limits to the kinds of shaping that parents are permitted to do by genetic means, and that those limits do not disappear in non-identity situations, then we would do well to avoid thinking about the limits to non-genetic shaping in terms of a battle or a balance between competing rights.

Of course, these conclusions will be less interesting to those who do not hold the moderate view of the child’s right to an open future, or those who believe that parents have far greater moral latitude to shape their children in non-identity situations than in other situations. Finally, those stalwarts who think that there is hope for solving the non-identity problem in ways that retain the claim that creating a child who is inevitably impaired by the events necessary to his or her very existence is nevertheless wronged will not feel the force of the problem posed here.

While I acknowledge that the problem I have explored, and the solution I have suggested, will not appeal to everyone, I hope that this exploration has served to illuminate a broader point that stands regardless of one’s acceptance—or not—of the position I have outlined. That broader point is that work on procreative ethics may intersect in interesting and unexpected ways with work on parental rights, especially when we begin to ask deep moral question about how far parents may go when they act on the fairly common desire to have a child who is a chip off the old block.
Fine Cuts of Moral Agency: Dissociable Deficits in Psychopathy and Autism
02:: Fine Cuts of Moral Agency: Dissociable Deficits in Psychopathy and Autism

Abstract

With a new understanding of the deficits of psychopaths, many have argued that psychopaths are not morally accountable for their actions because they seem to lack any capacity for fundamental moral understanding. And yet a lack of capacity for empathy, which has been seen as the root of this incapacity, has also been attributed to subjects with Autism Spectrum Disorder (ASD). But there is much anecdotal evidence that many with ASD have moral understanding and are rightly treated as morally accountable agents. Is it possible to explain how those diagnosed in the first group might lack, while those in the second group possess, moral accountability, given the commonly recognized shared incapacity for empathy? If so, how? In this chapter, I argue that there is an explanation that requires distinguishing between different kinds of empathy and that brings to bear a "fine cuts" approach at the neural and psychological levels of explanation.

1. Introduction

Let us start with a puzzle. Psychopaths can behave in nasty ways and can at times seem to take particular pleasure in harming others. But they also have a number of psychological deficits, including diminished capacities for remorse and empathy, and there is significant reason to believe that they lack genuine knowledge of moral principles. While controversial, it is for these reasons that there has recently been considerable movement toward treating psychopaths as not morally accountable agents. This is consistent with treating them as posing dangers to others who need to be protected, of course. But the idea that psychopaths simply cannot understand or act on moral reasons, and so do not have the basic abilities necessary for being held morally accountable for their actions, is a powerful one. If they really lack the relevant capacities to act on moral reasons, they seem as undeserving of being held accountable as, say, wild animals who also lack such capacities. In both cases, we need to protect people from the dangers they pose, but in neither should we hold them accountable for their actions. (I understand “appropriately holding accountable” to entail the appropriateness of making moral demands, such as the demand to act differently than one does, and of responding with so-called reactive attitudes such as resentment, indignation, and gratitude.) The puzzle arises because psychopaths appear to share a key deficit with those who are diagnosed with Autism Spectrum Disorder. Lack of capacity for empathy has been thought characteristic of the disorder (although, as we will soon see, what empathy amounts to is a subtle matter). And yet while it is natural to point to mitigating circumstances in many cases in which the behavior of ASD subjects harms others, there is much anecdotal and other evidence that many such subjects have the general ability to respond to moral reasons and in some circumstances may be fully morally accountable (whether blameworthy or
praiseworthy). If the same emotional deficit is at the heart of both conditions, then how is it that we can reasonably arrive at such different verdicts in the two cases concerning whether subjects are morally accountable? In other words, if we accept both premises (1) psychopaths are not morally accountable and (2) ASD subjects are morally accountable, then we need an explanation.

Before we explore solutions to the puzzle, it is important to note a couple of preliminary points. First, while it is clear from the label “Autism Spectrum Disorder” that it refers to a spectral condition, the same is also true of psychopathy, at least as currently diagnosed. Thus, it might be that the generalizations made about either condition hold only for a smaller subset of cases with the condition and also that where the psychological deficits are scalar, it might be that the moral deficits are correspondingly scalar. Also important is the fact that both conditions are currently diagnosed by symptoms of various sorts. It might turn out that we come to divide into two groups those who are currently diagnosed as psychopaths. For example, there are so-called successful psychopaths who seem to differ from the unsuccessful ones on at least one important dimension (i.e., living a conventionally successful life), and it might be that the etiologies are in fact different. Were we to move eventually to etiology, we would differentiate the diagnoses. But for now, we will make the assumptions that we have only two distinct conditions: ASD and psychopathy.

Second, it is also important to describe briefly the key features of each condition used in each diagnosis. The most widely used diagnostic tool for psychopathy is currently the Hare Psychopathy Checklist-Revised (henceforth, “Hare Checklist”), a two-factor model that takes into account personality traits and lifestyle traits (see the appendix to this chapter). Notably, it includes “lack of remorse or guilt” and “callousness/lack of empathy,” emotional deficits that have been thought to be at the root of the disorder. In addition to their performance on the Hare Checklist, there has been much discussion in the literature of psychopaths' weak performance on a well-known test for moral cognition, Turiel's moral/conventional test, that shows whether subjects distinguish moral transgressions from conventional ones (like using the wrong fork for a salad course). The test is commonly thought to measure moral knowledge.

The Diagnostic and Statistical Manual–5 offers the following as diagnostic criteria for autism (see the appendix for details):

persistent deficits in social communication and social interaction across multiple contexts and restricted repetitive patterns of behaviors, interests or activities, where these symptoms must be present in the early developmental period and cause clinically significant impairment in social, occupational, or other important areas of current functioning and are not better explained by intellectual disability or developmental delay.
Third, having already picked out the concept of moral accountability by its connection to the appropriateness of moral demands and the reactive attitudes, it might be thought that we ought to go further and adopt a more specific set of necessary and sufficient conditions for moral accountability. I favor a conception according to which one is morally accountable when one has fair opportunities to act well, or avoid wrongdoing. In turn, this requires both that situational factors cooperate and that the agent possess important normative capacities, including the cognitive capacity to discern moral reasons and the volitional capacity to be motivated by such reasons. Not everyone accepts this account of moral accountability, however. Interestingly for our purposes, even competing accounts require what appear to be some of the same conditions, such as the capacity to form certain sorts of morally salient judgments, such as those that would constitute judgments of regard or disregard for another person’s agency. Thus, in what follows, I will, unless noted, not assume a particular account of moral accountability.

With these preliminaries in mind, we can now turn to the puzzle itself. There are two main strategies for addressing it: Accept the two premises and go on to explain how and why this is, given that seemingly morally salient deficits are shared between the two groups, or reject one or both of the premises of the puzzle. In the next section, I canvas exemplars of each strategy. In the end, I tentatively conclude that accepting both premises is the most fruitful approach and that the evidence we currently have supports the existence of an important difference in moral capacity underlying the difference in moral accountability between ASD subjects and psychopaths. However, I do not think that previous attempts to explain why this is true have so far been fully successful. Thus, in the third section, drawing on insights from the suggestions canvassed, as well as from a general approach to psychopathy that I extend to ASD, I offer a tentative account that brings together what is, in my view, the best moral theory with a broad collection of the current empirical evidence. In the fourth section, I then show how the account and the approach might have further applications, and finally conclude by drawing some larger lessons about how best to approach the constellation of questions I’ve addressed here.

In particular, as the title of this chapter suggests, I advocate a “fine cuts” approach, taking inspiration from Uta Frith and James Blair. They compare fine distinctions in amygdala function to distinct psychological mechanisms, which we might otherwise miss if we simply focus on general similarities among the outcomes across different conditions. Seeing differences in brain function, say, between ASD subjects and psychopaths can help clue us in to different mechanisms and, in turn, to different cognitive deficits, despite the superficial similarities in affect and empathy that drive the puzzle. This insight might, in turn, help us to distinguish moral deficits that we might otherwise miss or, in other words, make finer cuts relative to moral
agency than we are used to doing. Interestingly, we can also work fruitfully in the opposite direction: distinguishing between different moral capacities can provide reason to seek different cognitive capacities and neural function that underlie them.

2. Two Approaches to the Puzzle

Accepting the Premises and Rejecting Empathy as a Requirement for Moral Accountability

In her rightly influential (2002) paper, “Autism, Empathy, and Moral Agency,” Jeanette Kennett argues for the bold conclusion that subjects with ASD show that empathy is not in fact a necessary condition for moral agency. I assume here that if one is not a moral agent, then one is not a morally accountable agent either. Thus, we can solve the puzzle by rejecting empathy as a requirement for moral accountability, but preserve (1) and (2), the premises that psychopaths are not morally accountable agents while at least some subjects with ASD are. The difference between them is due to something else missing in the case of the psychopath but intact in the ASD subject.

Kennett’s case has several parts. First, appealing to various forms of evidence, she makes the case that subjects with ASD have strong moral concerns. As evidence, she cites their ability to distinguish moral and conventional harms on Turiel’s moral/conventional test, as well as a rich variety of anecdotal evidence, including testimony from very high-functioning subjects who are able to reflect on and articulate aspects of their own condition. For example, Jim Sinclair, who has ASD, reflects eloquently on his mental processes as he realized that someone was sobbing and grief-stricken. He realized that he should do something to relieve the other’s distress but could not figure out what to do. Eventually, he realized that this was a situation in which “someone needed to be touched” (Sinclair 1992, 300). While Sinclair had trouble figuring out what needed doing, there is excellent reason to believe he recognized an important moral reason for doing something.

ASD subjects may be impaired in their ability to know that they are in a morally salient situation, but once they learn of the salient features (someone else’s distress, for example), then they take it as their end to respond in morally relevant ways. And yet they seem to have deficits in empathy, even as they themselves describe their situation (see Kennett 2002, 347–8). By themselves, these two claims present a powerful case that empathy—at least understood as Kennett does here, as a particular kind of emotional capacity—is not necessary for moral concern or for being able to act on moral reasons.

But it would help to explain how this is possible, and Kennett appeals to the Kantian idea that subjects with ASD are in possession of rational predispositions and
feelings in favor of acting for reasons. Because some reasons are moral, subjects with ASD can act for moral reasons and are thus capable of deep moral concerns. As Kennett writes, "They are capable, as psychopaths are not, of the subjective realization that other people’s interests are reason-giving in the same way as one’s own, though they might have great difficulty in discerning what those interests are" (2002, 354). It is in their capacity to act with a concern, even a feeling for, reasons, that underwrites ASD subjects’ moral agency—and, by extension, moral accountability.

While I will ultimately agree with much of what Kennett says here, I want to focus on two important challenges to the view. The first is that Kennett does not explicitly distinguish between different definitions of “empathy.” To see how this affects the view, note that psychologists have come to distinguish between, on the one hand, cognitive empathy, which is sometimes equated with Theory of Mind and which involves perspective-taking capacities that enable one to know and predict what mental states others have, and, on the other hand, so-called emotional empathy, which consists in one person’s feeling the same feelings that another does and at the same time believing that the same feelings are felt by the other (see Blair 2008; Roskies 2011; Bird and Viding 2014). Having made the distinction, we can see that there is a great deal of evidence that psychopaths have cognitive empathy and may even be especially talented in this area given their skill at manipulating others, while subjects with ASD often have deficits in this area. At the same time, subjects with ASD often have capacities for emotional empathy (at least in the circumstances in which they are able to pick up correctly on cues from others), while psychopaths have deficits in this area (Blair 2008). These different deficits might then be thought to dissolve the puzzle by rejecting the overly general claim that both groups suffer from deficits in empathy. Instead, once we distinguish between different kinds of empathy, we can see that the two groups do not suffer from the same deficit.

But while these empirical claims about the respective deficits of the two groups may very well be true, and while they might provide an initial framework for dissolving the puzzle, in my view they do not remove the sorts of fundamental questions underlying the puzzle. In particular, they do not explain how or why the different deficits can lead to different moral capacities and in turn to different verdicts about moral agency and moral accountability. Further, we can ask whether the relationship between the respective deficits and moral capacities is a contingent one, dependent on a particular human developmental path, or whether it is an intrinsic one, so that having the deficit in empathy directly entails a moral incapacity.

Before exploring these further questions, consider a second worry about Kennett’s view. To ground the idea that ASD subjects can act for moral reasons, Kennett suggests that the fundamental concern that makes this possible is a concern to act for reasons. On a natural way to understand this suggestion, one’s motive in acting well in
a given instance is ultimately a desire to act for reasons. The problem with this idea is that it is a substantive and contentious view that it is sufficient for acting for moral reasons that one simply desires to act in accord with some reasons. The worry here is that one might take the existence of rules to be reason-giving and so want very much to follow rules and do so, but not thereby act for particularly moral reasons. Importantly, there is anecdotal evidence that some ASD subjects stick with rules when they really ought to see that there are moral reasons for making exceptions. For example, there is the person with ASD whose allegiance to rules is so strong that he attacks the coat check attendant who mistakenly offers him the wrong coat, and there are others who fail to understand how there can be exceptions to rules even in circumstances that cry out for exceptions (see McGeer 2008 and Shoemaker 2015 for this point). Arguably, such persons act with a concern for reasons, but intuitively this seems insufficient for acting for moral reasons.

But there is a second way of understanding the suggestion, and, on this view, the concern with acting for reasons simply makes possible a further contingent ability to find and adopt moral reasons. Indeed, in later work, as I read it, Kennett (2008) suggests something like this idea. One challenge for the second way of understanding the suggestion is that we are left with an incomplete story about how it is that ASD subjects develop their capacities for acting on moral reasons. Kennett offers a speculative example of how the story might continue. When offered a scenario in which a child smashes a piano, ASD children with deficits in the ability to pretend-play correctly identify the action as morally and not merely conventionally wrong. But, lacking empathy and unable to imagine any potential victim’s point of view, by hypothesis, they must find another route to this conclusion. Kennett suggests the possibility that what is going on in this case—and the case in which there is a direct victim—is that ASD subjects take the object in question (the piano, the person) as an object of value and find something wrong in harming or destroying it (2008, 263). This is an interesting idea, but even if this were the correct empirical story about how ASD subjects come to classify the act as morally wrong, it is at best controversial that an ASD subject acting for these reasons is acting for moral reasons. It is controversial, for example, whether destroying a piece of art is wrong in any way, if there is no possible victim. And it is a further step to claim that doing so would be morally wrong. (See Dworkin 1993, who distinguishes these two kinds of claims.) In sum, this way of accommodating ASD subjects’ supposed lack of empathy of a kind that involves the taking up of victims’ points of view, while still recognizing their ability to grasp moral reasons, is a neat solution. However, at a minimum, it comes at the cost of making a commitment to substantive and controversial moral theory here, which would need defending.

Still, while the commitments to the particular moral theory might be
indefensible in the end, the general idea that psychopaths lack, while ASD subjects possess, a distinct faculty is intriguing, and we will return to it in the next section as a complement to the main suggestion previously discussed. The idea is to identify a capacity that is unrelated (or at least not directly related) to the relevant sorts of empathy and that divides psychopaths from ASD subjects. For now, let us turn to a very different approach to the puzzle.

The Rejection of One or More of the Puzzle’s Premises

A key premise for generating the puzzle is (2) ASD subjects are morally accountable agents. But this claim might be doubted, and if we focus on cases like the man previously described whose understanding of moral rules seems shallow in an important way, then this seems like a solution worth pursuing. Of course, there are cases and then there are cases, and it might be that while some ASD subjects lack moral agency and accountability, this is because they have some sort of additional condition (which is common) that is responsible for such moral deficits. Citing only a few cases will not suffice here.

So let us turn to a more developed argument for this conclusion. Beginning with the psychopath, David Shoemaker argues that the key to understanding psychopaths’ moral deficits lies in a particular kind of deficit of empathy. Further, while there may be some differences in the particular kinds of empathy that psychopaths and ASD subjects are capable of, in the end, both ASD subjects and psychopaths lack just the kind of empathy required for moral accountability.

Let us begin with the psychopath. While Shoemaker points out that a popular test for moral understanding, Turiel’s moral/conventional test, is flawed in a number of ways, he takes it that we can salvage something from the results. One of the dimensions on which the test sorts responses to scenarios as being either moral violations or conventional transgressions is that of “authority (in)dependence.” For example, when asked whether, if a teacher says it is permissible to wear pajamas to school, it would be permissible, most adults and children say yes. In contrast, when asked whether, if a teacher says it is permissible to hit another child, it would be permissible, they say no. One interesting way in which psychopaths differ from nonpsychopaths on this sort of question is that they treat both kinds of cases as on a par when it comes to authority independence. Shoemaker takes it that insofar as psychopaths have a problem, it is in understanding what he calls “victim-authorizations,” which is the capacity that underlies moral accountability. He suggests that, at least in key cases, if we make sure to correctly identify the potential victim in a given scenario, what determines whether we have a moral transgression is whether the victim has authorized a given action. So in a case in which someone is sincere, informed, and rational, and “says it was ok” to hit her, or pull her hair, or smash
her piano, or break her swing, then, according to Shoemaker, the behavior becomes permissible (2015, 155). In the event in which the person gives permission, she cannot make a legitimate complaint. In contrast, in the event in which the person does not give permission, she can make such a complaint, and it is appropriate for her to respond with anger (a response associated with holding someone accountable). In Shoemaker’s theory, the transgressor in this case has failed to show sufficient regard for, or in other words has failed to appropriately weigh, another’s specific normative perspective in his own. It is the capacity to do just this that is the condition (or at least a central one) for moral accountability in Shoemaker’s view. Psychopaths, lacking an understanding of victim-authorization, are not apt objects of moral accountability.

The inability to understand victim-authorizations can be seen to have a source in an inability to engage in what Shoemaker calls “identifying empathy.” While psychopaths are quite good at cognitive empathy, or mere perspective taking, they seem incapable of taking up “the normative perspective of [another’s] mind’s eye as my own in certain crucial respects” (2015, 158). This sort of empathy is a matter of seeing the others’ ends under the “guise of the good,” as they themselves see their ends. Psychopaths thus have deficits in identifying empathy, which takes both cognitive and emotional forms. But identifying empathy goes well beyond the mere taking of another’s perspective in a way that allows one to predict and manipulate behavior, and psychopaths are lacking in this ability in both of its forms. While Shoemaker takes this to be a third kind of empathy, we might take it to combine cognitive empathy with something else altogether, namely valuing, or at least the seeing of another’s ends as valuable in the way that they would see them.

Supplementing this analysis, Shoemaker points to the observation that many psychopaths seem impaired not only morally but prudentially, a point noted by Kennett as well. As Shoemaker puts it, psychopaths are evaluationally impaired generally, and this offers even more support to the idea that they are not able to engage in identifying empathy even of the cognitive sort, which in turn suggests that they cannot take up another’s evaluative point of view, which is itself essential for moral accountability.

Now the question is whether this same pair of deficits—in identifying empathy and in a more general ability to see any projects, even their own, as worthy of pursuit—applies to subjects with ASD. Shoemaker takes it that the answer to the first question is “yes;” subjects with ASD are deficient in the capacity for identifying empathy. When it comes to the second question, Shoemaker points out that while ASD subjects seem not to have the more general deficit that psychopaths do, they have a more limited one with respect to seeing value in others’ projects, and this is sufficient to put them in the same boat as psychopaths when it comes to limitations in moral accountability. To support the lack of identifying empathy in ASD subjects, Shoemaker
points to limitations in emotional empathy. Although subjects with ASD can express a wide range of emotions and they can be affected by others’ emotional responses, Shoemaker denies that this counts as genuine emotional empathy insofar as there is a tendency to remain unaffected by “the other person’s feelings as the feelings of another self with whom one is engaged” (Hobson et al. 2006, 135). In turn, Shoemaker takes this deficit to rest on a more fundamental inability to take up the perspectives of others in any real way. For this reason, even if ASD subjects do not suffer from the more general deficit that psychopaths seem to suffer from and can see their own projects as worthy of pursuit, the inability to take up the perspectives of others in any real way is sufficient to deprive them of the capacity to have the kind of regard for others that is essential for moral accountability.

While this is an intriguing solution to the puzzle and offers important insights, I believe that there are at least two main reasons to question it. The first simply acknowledges the anecdotal evidence that at least some subjects with ASD seem to be extremely articulate about their moral concerns, which go much deeper than the mere following of rules. As they describe it, they use rules to help them achieve those moral ends. For example, Sinclair describes himself after the episode with the grief-stricken person as developing “a separate translation code for every person” he meets (1992, 300). Second, and perhaps most importantly for our larger project of figuring out how to approach these deep and challenging questions, for Shoemaker’s argument to go through, it must presuppose a substantive but deeply controversial moral theory.

Recall that in Shoemaker’s view, it seems that once an agent has given permission for another to do something that is prima facie harmful (as in the punching case), it is morally permissible to perform that act. But this is a narrow view of what makes something morally wrong. As long as we recognize the fallibility of agents to recognize and act on their own interests, this focus on agents’ perspectives wrongly leaves out the idea that a person’s interests could generate reasons and obligations even when the person herself doesn’t recognize them. In Shoemaker’s own case in which he has the intuition that it is permissible to punch another if she says so, I have the opposite intuition. It could very well be wrong to punch someone even if from her point of view it was appealing (or at least not on balance bad) and the permission was given sincerely. And the reason for this is that there are at least two kinds of moral considerations on the moral theory I favor, namely, those concerning justice or rights and those concerning beneficence or welfare. If the account of why someone is wholly lacking in moral accountability is exhausted by an inability to recognize one of the two kinds of reasons, then the account can at most be partial. So we have a kind of dilemma for Shoemaker’s reasoning: Either the account is incorrect in being too restrictive an account of morality, or it is incomplete.

Interestingly, some accounts of the impairments of psychopaths emphasize only
the second of the two kinds of reasons—an inability to see the actual interests of others (as opposed to the interests others take themselves to have, perhaps mistakenly) as reasons. Shoemaker’s view nicely brings out the fact that this characterization of the psychopaths’ moral failings is also, arguably, incomplete. It is not a settled matter whether or not all moral reasons reduce to welfare (as utilitarians believe), for example. And given Shoemaker’s own commitments, he at least comes close to representing the opposite reductionist view at some points, namely, that moral reasons fundamentally reduce to respect for others’ permissions or lack thereof to do what they see as in their interests. While I believe that there are good reasons to adopt a view that recognizes reasons of both kinds, rather than try to offer a defense of that claim here, I want to note the importance of making explicit one’s theoretical moral commitments in judging whether or not someone is capable of acting on moral reasons. In turn, this can have direct implications for what sorts of psychological capacities one takes to be necessary for moral agency and moral accountability.

Taking stock, we have seen that while Shoemaker’s and Kennett’s views are fundamentally opposed to each other, it turns out that they both make very particular moral theoretical commitments about what we ought morally to do and why. On the one hand, Kennett’s view of moral reasons is so inclusive that it might include ASD subjects as capable of acting on moral reasons when it should not insofar as it counts impersonal reasons of a sort that could apply to pianos and persons equally as moral. On the other hand, Shoemaker’s view of moral reasons could turn out to be so restrictive that it might exclude ASD subjects (and psychopaths) from moral accountability when it should not to the extent that it restricts moral reasons to authority-dependent reasons of justice.

At the same time, both Kennett and Shoemaker provide key insights. Before turning to these, it remains to consider the rejection of the first premise in the puzzle, namely, the claim (1) that psychopaths are not morally accountable. One might argue that Shoemaker was right to assimilate the two cases but that, contrary to Shoemaker’s further claim, both psychopaths and ASD subjects are morally accountable. And, indeed, some of the original reasons researchers have asserted that psychopaths are not morally accountable have proved to be undermined.

Recall, for example, that one of the original reasons for thinking that psychopaths were not morally accountable was their poor performance on Turiel’s moral/conventional test. If they truly cannot sort moral and conventional transgressions correctly, then they appear to have a serious cognitive incapacity, one that calls into question whether they have the relevant moral concepts at all. But further refinements of the test in a forced-choice form show that diagnosed psychopaths actually can sort cases as well as others. Their original missorting seems to have been due to their overinclusion of cases in the moral category in an attempt to
impress their testers with how moral they are. Thus, one of the main pillars of support for the premise about psychopaths is no longer standing.

Another piece of evidence often cited in favor of psychopaths’ lack of moral accountability is their seeming inability to care about doing the right thing, which has been interpreted as evidence that they are *motivationally incapacitated* from doing the right thing. But as David Brink points out in his illuminating discussion of psychopaths, the fact that psychopaths do not act well or do not care enough about doing so does not entail that they cannot do so (2013, 37–38). They do not seem to have complete volitional impairment across the board, for example. And in fact they can often act in accordance with moral norms for stretches of time.

If both kinds of evidence turn out to be flawed, then perhaps the solution to the puzzle is to simply reject the premise that psychopaths are not morally accountable. But while this particular evidence for the premise is problematic, we haven’t been shown that the premise is false. To see this, note that while it is surely right that psychopaths’ performance on the test cannot be used in the way it has been to support the premise that they are not morally accountable, mere correct sorting of the moral and conventional is not sufficient for supporting the contrary claim either. For example, someone might have learned all of the moral rules on Tuesdays and conventional rules on all the other days and knows that the moral ones are the Tuesday-learned ones. But this wouldn’t show the kind of genuine moral knowledge that seems to be required for moral accountability. And while it is also true that failure to conform to moral norms is not decisive evidence against the capacity to do so, it is also true that there is anecdotal evidence that psychopaths simply are not working with the same conceptual framework as the rest of us. For example, in a chilling but not atypical passage from Robert Hare’s *Without Conscience*, a psychopath describes himself as follows:

**Do I care about other people? That’s a tough one. But, yeah, I guess I really do . . . but I don’t let my feelings get in the way . . . I mean, I’m as warm and caring as the next guy, but let’s face it, everyone’s trying to screw you . . . Do I feel bad if I have to hurt someone? Yeah, sometimes. But mostly it’s like . . . uh . . . [laughs] . . . how did you feel the last time you squashed a bug?**

This passage is subject to interpretation, but at least one natural reaction is that there is a lack of understanding of what it is to be a ‘warm and caring’ guy, and *a fortiori* of what sorts of ends a warm and caring guy aims at. There is a glimmer of understanding of what his interlocutor would like to hear, but that is not the same thing. In sum, then, while it is true that some of the original reasons that researchers put forward for the premise that psychopaths are not morally accountable agents are problematic, there remains some evidence in favor of the premise. At the least, the case is not closed against the premise.

Taking stock, then, it seems that attempts to reject each of the two premises are
either unsuccessful or indecisive. In the next section, then, I will return to the project of seeking an explanation of how the two premises could both be true. If we can find a plausible explanation of this kind, it can provide mutual support to the premises themselves.

3. Finding a Plausible Substitute for Empathy as a Way of Grounding Differential Moral Capacities

Let us begin with an insight that starts with the observation, made by Cleckley in the 1940s and discussed by others since, including Kennett and Shoemaker, that psychopaths tend to suffer not only from moral deficits but also from prudential ones. As Cleckley concludes, “In contrast with all the various diversities of viewpoint and degrees of conviction found among ordinary people, the so-called psychopath holds no real viewpoint at all and is free of any sincere conviction in what might be called either good or evil” (1976, 371, note). This idea is developed most recently in its most sophisticated form by Watson (2013).

The basic idea, or the "linkage thesis," as Watson puts it, is that the psychopath’s deficits in moral concern and prudential concern have a common explanation. As Watson writes:

The thought that prudential and moral concerns are bound up with one another is not unfamiliar in philosophy, and we find in philosophical moral psychology, and current theory of agency in particular, a cluster of ideas that might help us capture what is amiss with psychopathic agents: that they are deficient in the capacity to care or to value; that they are wantsons or lacking practical identities … [T]he common ground of the prudential and moral failures of psychopaths is the incapacity for a reflective normative orientation. I am primarily concerned here with practical normative orientation … by which I mean standards of action, intention and desire that entail the possibility of conducting oneself badly or incorrectly, and hence serve as the basis for self-criticism and correction.

(2013, 275–76)

The common explanation of the moral and prudential deficits, then, and the crucial missing piece for the psychopath, is the ability to reflect on one’s actions in a way that allows for judgments that one has acted badly or incorrectly. This is a very general deficit and is thus more general than a moral one.

While Watson does not apply this idea to the puzzle concerning psychopaths and ASD subjects, we can turn to that task here. Subjects with ASD display a clear normative orientation in many cases and do not seem to suffer from the kind of
inconsistency in practical reasoning that psychopaths do. For example, some seem to desire to avoid punishment and very much dislike it, and yet the desire does not seem to influence their behavior.

Note that this way of distinguishing psychopaths from ASD subjects does not require any commitment to a particular moral theory. Far from appealing to an arguably overly narrow or overbroad account of moral reasons, this approach identifies the deficit in question as explicitly encompassing failures broader than that of the moral. But if it is appropriate to the cases, then we should welcome such an explanation.

Some important questions remain, however. For one, it would be helpful as a further test of the hypothesis concerning the scope of psychopaths’ deficit in being able to take up a normative perspective to connect the failure to other, perhaps lower-level, psychological deficits (and, perhaps ultimately, to neural structure). As it is, empathy plays no prominent role in explaining the very general deficit hypothesized here. Is there a replacement to be found? Or could we see that empathy of one form or another plays some contingent, albeit robust, typical developmental role? Perhaps we should return to the apparently real differences between psychopaths and ASD subjects when it comes to different kinds of empathy for insight here after all.

Importantly, there is perhaps an even more promising place to look for a developmental difference that can explain the differential capacity in taking up normative perspectives, namely, the capacity for a certain kind of learning. As Blair writes:

**There is evidence of a clear “fine cut” between psychopathy and autism with respect to stimulus-reinforcement association formation. Individuals with autism show no impairment of this function of the amygdala.**

(2008, 165; see also Blair 2015)

Thus, there is a deficit in psychopaths that is not present in ASD subjects and that can be seen at both the neural and psychological levels. And this dovetails nicely with a claim made by Elliot in his elaboration of something like the common ground account of the psychopath’s deficit:

**This poor judgment seems to stem not so much from the psychopath’s inadequate conception of how to reach his ends, but from an inadequate conception of what his ends are. He seems neither to learn from his adverse experiences nor to plan for the future.**

(1992, 210)

It might be that the psychopath’s impairment in stimulus–reinforcement association plays a role in a developmental explanation for the failure to acquire the capacity for taking a normative perspective. Not being able to mark features of
situations as 'bad' for future use would seem to be potentially relevant in developing a normative perspective from which one can see the need for self-correction. The appeal to stimulus-reinforcement deficits in psychopaths helps explain the idea that psychopaths and ASD subjects differ in fundamental ways. The former, but not the latter, are impaired in their ability to take a normative perspective, and, for this very reason are impaired in the capacities needed for moral accountability.

4. Conclusion and Further Applications

I began by canvassing two intriguing approaches to the puzzle, one that accepts the premises of the puzzle and explains how they can both be true by denying that empathy is necessary for moral accountability and one that rejects one or both premises of the puzzle.

Though each contains important insights, each also faces challenges (e.g., the first does not distinguish between different kinds of empathy while at least one variant of the second undermines intuitive responses in at least some paradigm cases), and despite their fundamental differences, variants of each approach share a reliance on substantive and controversial implicit moral theories. Adopting a shared insight, namely, that psychopaths appear to be lacking an ability to value not only in moral contexts but also in prudential and other contexts, I suggested that this is the key to distinguishing the moral status of psychopaths and ASD subjects. Importantly, taking a fine cuts approach at the neural and psychological levels supports this difference between members of the two groups. And it succeeds without having to adopt a controversial and specific moral theory.

At the same time, it is important to note that even if this approach to the puzzle allows us to avoid having to defend commitments to particular moral theories, such as whether moral reasons reduce to considerations of welfare or instead to consideration of rights or autonomy, it does not follow that there are no circumstances in which the fine cuts approach will force us to do just that. The discussion thus far shows that there are interesting questions about whether there might be actual (or even just hypothetical) creatures who can act for some kinds of, but not all kinds of, moral reasons. For example, the case of those with a behavioral variant of prefrontal dementia, which, as Agnieszka Jaworska argues, is characterized by a dissociable deficit in the ability to care, raises the question of whether those with such a diagnosis are incapacitated for acting on all moral reasons or just some. Are there even finer cuts to be made with respect to domains of moral accountability? Although answering these questions goes beyond the scope of the chapter, I hope to have shown how a fine cuts approach can help illuminate a search for answers that relies both on philosophical inquiry and an understanding of distinct psychological capacities.
What Are Parents For? A Thought Experiment
03:: What Are Parents For? A Thought Experiment

As Milton’s Adam observes in a fit of pique after his fall from grace, one of the things that parents do for children—analogizing God as father and mother both—is to presume to bring them into being. (When I refer to parents in the following, I normally have in mind parents qua procreators, as the context should make clear.) Neither informed consent, nor even mere assent is, of course, possible on the part of children-to-be. Moreover, once we are here, whenever that strange and remarkable event occurs in our development, there is no not having been here, and there is also no easy means of exit should we not be happy with the course that our lives are taking. In Adam’s words (in verse that reappears, significantly, as the epigraph to Shelley’s Frankenstein):

Did I request thee, Maker, from my clay
To mould me Man? Did I solicit thee
From darkness to promote me . . .?

The lament is ancient. Nietzsche refers to the “ancient story” of Midas’s capture of Silenus—and Silenus’s cackle that “[w]hat is best for [human beings] is beyond [our] reach forever: not to be born, not to be, to be nothing”: “Job wishes that his creation could be undone in language that inverts the creation story in Genesis 1:

Let the day perish in which I
was born.
and the night that said,
“A man-child is conceived.”
Let that day be darkness!
May God above not seek it,
or light shine on it.
Let gloom and deep darkness
claim it.

Philip Larkin’s vision in his oft-quoted poem “This Be the Verse” is funnier but perhaps even darker. I pass over the infamous first line (which as a rule is all that is ever quoted) for the final stanza:

Man hands on misery to man.
It deepens like a coastal shelf.
Get out as early as you can.
And don’t have any kids yourself.

This last bit of advice is presumably for “the good of the child”; the poet or, in any event, the poem appears to deem all human life wrongful life. It is, obviously, an extreme judgment, and most bioethicists do not go nearly so far. Then there are the paradoxes that cluster under the bristling name of the non-identity problem. These
appear to dissolve the worry that parents can *harm* a child in bringing him or her into being, and so absolve would-be parents of any culpability for a child's existence in all instances but when it can be predicted that the child's life would be so terrible that it would not even be worth living. The non-identity problem takes its name from the supposition that "in different outcomes"—for example, when parents conceive a child now though this child will have a disability (outcome 1) rather than delaying several months, in order for the problem in question to pass, and having a child without this disability (outcome 2)—"different people would exist." In these different outcomes, to restate the point in different terms, the people who stand to come into being would not be identical with one another. Accordingly, it is not the case that the child with the disability might have been brought into being without this disability if only her parents had delayed trying to conceive; instead, if her parents had delayed, this child would never have existed at all. The only way for her to come into being was to come into being with her disability; and so (here is the kicker) it appears not to make any sense to say that her parents *harmed* her, which is to say acted against her interests, though they knew that she would come into being disabled. If we want to say that the parents committed some crime, it appears to be a crime without a victim. For the only alternative for the child, to speak nonsense for a moment, would be never to have come into being—which is nonsense since nonexistence is obviously no alternative for *her*. Yes, nonexistence might be *preferable* for her if we could predict that she would not have a "life worth living"—if the "bads" of that life would overwhelm any goods in it, or her existence were so terrible that it constituted an evil to her; but no, existence would not be worse for her than never having existed—she would not, strictly speaking, have been harmed in being summoned from darkness to light, to recall the imagery deployed by Adam and Job.

In bioethics, the non-identity problem is often deployed against those who, in the interests of children, would put limits on would-be parents' reproductive liberty. In other words, it appears, not as a problem to be solved or circumvented, but as an argument used to dismiss objections to reproductive decisions made before a child is conceived or very early in its development. For example, according to John Harris, 

"[t]here is no complaint the 'victim' of gender selection [or surrogacy, or artificial insemination by donor, or cloning] can make because for her there was no alternative but never to have existed." In fact, he goes on:

**the same is true for any significant genetic manipulation that might be made to an embryo or indeed to the gametes prior to conception, if this ever becomes possible. So complaints that parents who use gender selection are attempting to shape or mold their children [and thereby potentially harming them] are simply incoherent. [The parents] may of course be choosing what sorts of children will come into existence, but none of those children have any**
legitimate or even coherent complaint, for they could not have had an alternative life free of such externally imposed choices.

Yet not all objections to reproductive decisions need turn on the interests of the children so produced; the non-identity problem, retooled as an argument, does appear to undercut this kind of objection, but only this kind. It is a basic thesis of this book that parents, qua procreators, have obligations regarding future children that constrain the liberty of would-be parents to do as they wish. Moreover, these obligations go beyond respecting the oft-invoked child’s right to an open future. If it is objected that a person cannot have the obligations of a parent until a child, in fact, exists, the reply should be that, while yes a person would not have obligations to the child until she exists, a person is obligated not to create a child unless that person has a reasonable belief that he or she will be capable of carrying out the relevant obligations and is committed in advance to doing so. Analogously, a person does not have the obligation to repay a debt until he or she in fact borrows money. But that person would be wrong to borrow the money without a reasonable belief that he or she could repay the debt and without being committed in advance to the repayment. The upshot is that, if we have reason to think that a reproductive decision would lead to the violation of parental obligations, then we can object to this decision without having to engage the paradoxes of the non-identity problem. Whether the parents who bring a child into being thereby incur the obligation to do any of the work of parenting themselves is a further question that this chapter goes on to investigate.

One way to elaborate my thesis is to think about adoption, and so this chapter proposes to do so. As Jonathan Glover has observed, the model of adoption is potentially misleading for thinking about reproductive decisions. For the child who is available for adoption already exists and so decisions concerning this child—for example, with what parents to place him or her—can harm his or her interests; not so the child who cannot come into being but in this particular condition with these particular parents. I want, however, to come at adoption from a different angle. It has traditionally been held, at least in cultures shaped by the several Abrahamic religions, that what can be permitted and may be the better course in extremis —namely, giving up a child—cannot be justified in ordinary circumstances, which is to say when there are not very good and pressing reasons, even if one could be confident that another individual or for that matter institution could do the job of raising one’s child just as well or even better. In other words, so-called abandonment—richly studied by the historian John Boswell in his book The Kindness of Strangers—is justifiable in some circumstances, but not all circumstances, again even if others could do the job just as well or even better. But why? I put the question this way: why would it be wrong—if indeed it would be wrong—for a couple to seek to conceive a child with the idea, in advance, of giving him or her up simply at will, which is to say without some reason
other than that they wanted to do so? (In more current terms: why would it be wrong—if indeed it would be wrong—for a couple to plan to have to make an adoption or birth plan?) Trying to answer this question requires us to think about, not just what parents do for children, like presume to bring them into being, but what obligations becoming a parent brings: in the colloquial terms of this chapter’s title, “what are parents for.” Once we have this account, which I think would be valuable in and of itself for our appreciation of the role of parent, we can go on to consider in chapters to come whether, or under what circumstances, new ways of becoming a parent now and in the future—through gamete donation, surrogacy, and prenatal genetic enhancement—are likely to be compatible with the obligations of parents, qua procreators, to children. But first, in this chapter and the next, there is no little groundwork to be done. To prepare the reader, my argument in this chapter takes more than one twist and turn, and it is not until chapter 2 that the argument comes to a close.

1. The Tradition and the Two Answers

Alan Donagan articulates what he calls the “precept of parental responsibility” in the Hebrew-Christian tradition as follows: “It is impermissible for human beings voluntarily to become parents of a child, and yet to refuse to rear it to a stage of development at which it can independently take part in social life.” He further remarks that “[f]or a child whose natural parents cannot assume this authority, for any reason from death to temperamental unfitness, other arrangements must be made, for example, adoption; but they are considered to be intrinsically inferior.” Parental obligations or duties are then what are termed prima facie, which is to say obligations or duties that obtain not absolutely, but on the condition that there are not overriding considerations. In other words, according at least to the Hebrew-Christian tradition, procreators are prima facie obligated to parent the children whom they bring into being and so to carry out the duties of parenthood, whatever they may be (which at this point I do not presume to say). Remarkably, Jewish, Islamic, and the common law do not even have the category of adoption and instead only foster care. By contrast, “Modern American law (like the Code of Hammurabi, Roman law, and the Napoleonic code) has full legal adoption.” The 1851 Massachusetts Act to Provide for the Adoption of Children, which became the model statute across the United States, declared the adopted child “the same to all intents and purposes as if such child had been born in lawful wedlock of such parents or parent by adoption,” while terminating the so-called natural parents’ “legal rights . . . as respects such child” and freeing him or her “from all legal obligations of maintenance and obedience, as respects such natural parent or parents.” The growing practice of open adoption since the 1980s is, of course, introducing significant changes to this model as well as challenges to the adoptive family; but the background for these
changes and challenges is adoption understood more or less as the Massachusetts act conceived it.

Given the great changes in matters familial and sexual over the last fifty-plus years, it might come as a surprise that the traditional precept that Donagan articulates appears more or less to reflect common morality today, at least within cultures descended from the Abrahamic religions. Though it is legally permitted, giving up a child for adoption when one is competent to care for the child and there is nothing untoward in one’s life circumstances is seen as morally suspect. Donagan’s claim that other arrangements like adoption are “intrinsically inferior” to rearing by birth parents has not fared as well, though it has perhaps fared better than it should. Recent empirical research supports the view that, as Elizabeth Barthelet puts it, adoption “should be recognized as a positive form of family, not ranked as a poor imitation of the real thing on some parenting hierarchy.” After all, a child’s birth parents may prove terrible, and it can be a mercy to be given into the care of others, even the care of strangers. In any event, the current consensus appears to be that giving up a child for adoption may be commendable—indeed, it can be seen as “the last in a series of actions meant to provide care for the child”—but must also be undertaken with great seriousness.

At least one contemporary practice—namely, surrogacy—may well tell a different story, but I want to put it aside for now in order to focus instead on my question of why it would be wrong, if indeed it would be, for a couple to seek to conceive a child with the idea of giving him or her up simply at will, which is the case neither in so-called traditional surrogacy (where the mother contributes both genes and gestation) nor in gestational surrogacy (where the mother contributes “only” gestation). Admittedly, the question is somewhat strange, perhaps even disturbing: for many birth parents, the decision to give up a child is traumatic, even tragic in some sense. As Paul Lauritzen has observed in a thoughtful and well-documented discussion, “many children surrendered for adoption are not in fact unwanted by their biological parents, but are relinquished anyway because there is no alternative” in the face of unrelenting poverty, which was likewise often the case when children were “abandoned” in Antiquity and the Middle Ages. It should also be acknowledged that giving up a child has proven quite difficult for some surrogates, as several highly publicized court cases might be called on to attest. All the same, I propose that thinking about the question of why it would be wrong, etc., can prove instructive. For it calls on us to think more deeply than we typically do about both the grounds and content of procreators’ obligations to children. (Note that, in this chapter, I do not distinguish among procreators, birth parents, and biological or genetic parents. Once we turn from the case of a couple conceiving a child to consider procreation through gamete donation and surrogacy, these terms will need to be pried apart.)
One of the few authors who has spoken to my question, though briefly, is Leon Kass. According to him:

We practice adoption because there are abandoned children who need good homes. We do not, and would not, encourage people deliberately to generate children for others to adopt, partly because we wish to avoid baby markets, partly because we think it unfair to deliberately deprive the child of his natural ties.

So here are two possible answers to why it would be wrong for a couple to seek to conceive a child with the idea of giving him or her up: first, interpreting somewhat, it would reduce the child to a thing, or in Kantian language a mere means to some purpose (in a word, sale); and, second, it would deprive the child of “his natural ties,” or what Kass also calls a knowledge of his “roots.” Such knowledge, Kass claims, is of “profound importance . . . for self-identity.” “Clarity about your origins,” he writes, “is crucial for self-identity, itself important for self-respect.”

To speak to the first answer: would a child who had been conceived with the idea of giving him or her up, whether for money as in some surrogacy arrangements or as a gift in adoption, necessarily be treated merely as a means and not also as an end in him or herself (that is, someone whose own good deserves respect)? This conclusion, which is often drawn in discussions of traditional surrogacy, might seem inevitable. In the rather strong words of one author, such surrogate mother arrangements, “of necessity, treat the creation of a person as the means to the gratification of the interests of others, rather than respect the child as an end in himself.” The surrogate mother, “[b]y the very nature of the transaction,” cannot “make a pretense to valuing the child in and for himself, since she would not otherwise be creating the child but for the monetary and other . . . considerations [that] she receives under the surrogate mother contract.”

Once we think some, however, about the meaning of the Kantian imperative to treat persons “always at the same time as an end and never merely as a means,” then the judgment that the child is necessarily treated merely as a means appears less certain. On one common interpretation, “We use others as mere means if what we do reflects some maxim [that is, policy] to which they could not in principle consent.” Paradigmatic examples include deception, coercion, and violence. In deceiving someone, one involves another in a project to which he or she cannot in principle consent, since it must be concealed; in coercing someone, one makes someone do something to which he or she cannot in principle consent, since he or she has no real choice; and in doing violence to someone, one attacks and damages or destroys another’s very capacity to give consent. Now, it is not at all obvious that a child conceived with the idea of giving him or her up could not in principle consent—though only after the fact, of course—to the maxim on which his or her mother is acting. It is
true that we cannot presume his or her consent to such a way of coming into being, which might well make for a difficult life; but this is a different kind of objection (it does not challenge the permissibility of the action on Kantian grounds), which what's more appears vulnerable to the non-identity problem. Imagine John Harris asking: just how bad a life would it likely be? And then telling the child: you have no legitimate or even coherent complaint. Seeking to conceive a child with the idea of giving him or her up does not, then, appear wrong on the Kantian ground that it treats the child merely as a means.

Perhaps, though, a surrogate treats the child merely as a means in some less technical, non-Kantian sense: after all, whether we want to say that she is paid for the child or paid for carrying and then birthing him or her, the surrogate does have the child for some purpose to which the child is subordinate. In brief, the child is “just used” by the surrogate. Commercial surrogacy uneasily mixes what Virginia Held calls “the paradigm of economic man,” who organizes life in contractual terms, with “the paradigm of mother and child,” bound by affection. It is not obvious, however, that having a child for some purpose to which the child is subordinate is necessarily wrong. Imagine a woman or man who agrees to have a child with his or her partner in order, principally or even exclusively, to make that child-loving partner happy. Though the child is “just used” in this regard, doing so does not appear wrong, and the child is in fact valued as an end by at least one party to this decision, namely, the partner who desperately wants him or her. (In more technical terms, the child-loving partner sees the child as a nonderivative source of reasons: the reason to have a child is not derived from consideration of other reasons, as it is for the other partner.) Likewise, in surrogacy arrangements, at least one party values the child as an end, namely, the parents or parent who takes this child as his or her own. So in sum: the first possible answer to why it would be wrong to seek to conceive a child with the idea of giving him or her up does not appear sufficient. For the child so conceived is not necessarily treated merely as a means in a morally objectionable way. (There is of course much more to say about surrogacy; I focus on commercial surrogacy at some length in chapter 4.)

To speak to the second answer: Kass does not explain why knowledge of roots, or clarity about origins, is so important for self-identity, but it seems right to say that such knowledge does matter deeply to some people, though not to all. In any event, as another author has noted in analyzing the language both of professionals and of “some adopted children,” the problem here is certainly not the problem of personal identity discussed by philosophers like Locke and Hume. Instead, the literature tends to refer to psychologist Erik Erikson’s conception of identity as “confidence in one’s inner continuity amid change.” On this account, to have an identity means to be secure in who one is, or in other words, again speaking somewhat colloquially, to have a strong sense of self. Yet this kind of identity, some claim, is precisely what adopted persons lack. In the words of a leader of what has come to be called the search movement:
Adopted children have little continuity in their lives; for the most part, they have been cut off from, or have little knowledge of, the past. Their identities are fragile—whether they are adopted as newborns or later—and have been shaped by the trauma of separation from the birth mother, as well as by feelings of abandonment and the lack of a coherent life narrative.

We need to be wary, however, of agreeing too quickly with such claims. It is striking that advocates of the so-called new psychology of the adopted, like the activist quoted, show little awareness of what another author has termed “the cultural contexts in which [experiences of adoption] are embedded,” but freely make claims about adopted persons’ universal needs. If some adopted persons disagree about these needs, they are characterized as repressed. The story of “the search,” motivated by the sense that “something is missing,” has become a common tale in recent years, part of the pathologizing of adoption that has gone hand in hand with the return of an obsession with genetics. Though Kass would be horrified to hear it, his equation of “natural ties” with biological ties appears to belong to this trend. By contrast, as two critics of Kass’s argument have observed, “natural connection”—connection that deepens as the child grows up—“might also be created through needs-fulfillment.” In other words, rearing too might create deeply rooted relationships and so give a child a deeply rooted sense of self.

There are, of course, multiple reasons why adopted persons search for their birth parents, including to gain information about genetic health history and to come to terms with “concerns about why they were ‘given away’ or ‘given up.’” Pace the “new psychology of the adopted,” however, knowledge of biological ties does not appear in all cases essential for a person to have a strong sense of self, though some adopted persons do at times feel a strong need for this knowledge (for example, before beginning a family themselves); and the need should not be dismissed as “merely” a cultural artifact—as if, were the need “merely” cultural in origin, it would thereby be less real. Whether it would be wrong deliberately to bring into being a child who would be deprived of this knowledge, or would need to search it out, is certainly debatable. One way or the other, though, this objection does not seem to go quite to the heart of the matter.

2. The Given Relationship

It might appear that we have not gotten very far toward answering my question (why would it be wrong for a couple to seek to conceive a child with the idea of giving him or her up), but I want to consider further the reasons why adopted persons search for their birth parents. I listed two motivations: to gain information
about genetic health history, and to come to terms with "concerns about why they were 'given away' or 'given up.'" Now, persons whose adoptions were open instead of closed, as most adoptions used to be, do not typically have these motivations: the genetic information is already available, and they often know why their birth parents chose adoption. Yet it is remarkable that many of these persons search for their birth parents nonetheless. (Some, of course, know and have relationships with them already.) According to several researchers, "As more information is shared with children, it ... does not negate curiosity about their birth-parents.... During adolescence, this curiosity can lead to strong intentions to search and searching behavior." Why?

It ought to be acknowledged that the answer might simply be adolescent angst. In other words, perhaps the adolescent who searches for his or her birth parents has simply latched onto the fact that is most mysterious about him or herself, comparable to an adolescent who becomes fascinated with, say, a parent's abandoned culture or religion. But the reasons appear to go deeper, as suggested by the fact that the desire to discover one's birth parents is attested in cultures unacquainted with our teenage wastelands or the figure of the adolescent.

Onora O'Neill has suggested another answer: "It is evident," she writes, "that given relationships matter deeply to people." By "given," understand relationships that cannot be undone, or that have an ineluctable permanence. Paradigmatic examples include the non-adoptive parent-child relationship and that between siblings: the biological ties cannot be broken, though of course the relationships may be emotionally broken or severed in other ways. The contrast is with chosen relationships, the paradigmatic examples of which include friendship and modern-day marriage. In given relationships, the parties need to work on the relationship to make it happy, but it is there, at least in a sense, whether they work on it or not. In chosen relationships, the parties typically need to work to make the relationship happy if it is to be there at all, which is to say if it is not to dissolve altogether. To put the point in brief, persons can be former friends, but not former siblings. As evidence of the profound importance of given relationships to people, O'Neill observes that

adopted persons, even when they have had happy childhoods and love their adoptive parents, often want to make contact with their birth parents. Often they speak of the longing to know their birth parents as becoming stronger over the years, and as particularly strong when they have children of their own.... They may also want to know of and to know any (half) brothers and sisters, or any other genetic relatives. Although one often hears of adopted parents who explain to their children that they were chosen, this fact clearly does not always expunge the sense of loss, the sense that from the child's point of view, it would have been better not to have been chosen, but given.
Why given relationships matter so much to people is another question. To begin with, these relationships provide the *setting* for our lives: they give us the terms through which we may place ourselves—for example, as the child of these parents, or as the sibling of these brothers or sisters—an echo of Kass’s observation about the importance of knowledge of “roots.” Further, as Claudia Mills has observed, given or what she terms unchosen relationships form a bed for the development of relationships marked by unconditional love—more fully and precisely, love that attaches more to a person’s being, to the sheer fact of the person’s existence, than to his or her features or accomplishments and failures. By way of example (for there is no denying that this love is rather mysterious), it is a remarkable fact that an expectant parent can love a child before he or she is even born, which is to say before the parent knows much at all about the child, including whether the child is a he or a she. This kind of love is based more on the child’s *being* (yet more precisely, the child’s being the parent’s) than on any characteristics that he or she has or will develop. Barring confusion at the hospital over whose child is whose, or deception over paternity, the one “condition” of this kind of love is not a condition that could be disappointed and so in a sense is not a condition at all: it is the given relationship between the parent and child, that the child is the parent’s and the parent is the child’s.

Joseph Kupfer has insightfully suggested that the ground of the unconditional love of parents for children may be what he calls parents’ *identification* with their children: the fact that a child’s well-being and suffering “is experienced as constitutive of [a parent’s] own well-being and suffering.” For the loving parent, the child is “another oneself,” to use Aristotle’s characterization of the friend, in a way deeper than even the friend is. Again to explain by way of example, whereas friends grieve with us, “parents don’t just grieve with us; they also grieve for us,” and so need consoling from their friends when their children suffer. In the ideal, a parent loves a child in much the same way and on much the same grounds that the parent loves him or herself: not conditionally, but as part and parcel of his or her being. (We could also say, I think, by virtue of being.) Kupfer further claims, and here too I find him insightful, that the love of child for parent is, even in the ideal, not this same unconditional love. Instead, ideally, a child’s love for his or her parent is grounded in the child’s gratitude to the parent—gratitude for the fact that the parent has proved “a protecting, nurturing, unconditionally *loving* authority.” Of course, there should be no illusion that the ideal of parental love is always realized. To repeat, given or unchosen relationships form a bed for the development of relationships marked by unconditional love. In other words, they hold this potential, which may or may not be actualized. It should also be recognized that what we call unconditional love is in fact fragile and perhaps rarer than we might like to think. One philosopher has us imagine a child who proves rapist, serial killer, or torturer. As the pain of a thankless, or worse, older child may break the human heart,
when I speak of unconditional love in the following, I mean love that is unconditional to the extent that is humanly possible.

An important question to consider here is what role a child’s being the parents’ own—that is, the given relationship between parents and child—plays in the parents’ coming to love the child by virtue of his or her being (otherwise put, as they love themselves). In other words, how does the biological tie lead to or at least support parents’ identification with their child? A plausible answer, I think, is that parents come to identify with a child because they see him or her (indeed, for the mother especially, experience him or her) as an extension of themselves: in poetic terms, bone of our bone, flesh of our flesh. The child is naturally seen as “another oneself” because he or she bears and shows forth the parents’ own life, individually and as one flesh themselves.

Why it is important that children enjoy given relationships—more precisely, that children have relationships as they grow up that they can count on as given, whether these relationships have any biological component or not—is suggested already by the preceding reflections. To quote O’Neill again, “knowledge that the parent will persist”—will stick with or stand by the parent-child relationship—“is of great importance to a child’s . . . sense of security and belonging.” Moreover, the normative unconditionality of the parent-child relationship (note that this unconditionality holds for the parent, not the child) gives a child a sense that he or she is of great value, which is to say so valuable that the parent will not give up on him or her for any but the most trying causes. (The child who proves serial killer or torturer makes it clear that, while unconditionality is the rule, the application of the rule has its limits.) It is noteworthy in this regard that a “sense of rejection . . . usually accompanies most parent-child separations” and that “the sense of rejection, of not being wanted or being a ‘cast-off,’ seems to undermine [some adopted] children’s sense of self-esteem and self-worth,” even when they have been lucky enough to find, or more precisely to be found by, parents who provide love and acceptance. It should immediately be added, however, that not giving up on the relationship does not exclude letting the child go, or making him or her leave, should the child’s behavior make living with that child extremely difficult or practically impossible. What is distinctive to a relationship that can be counted on as given is that the offer of the relationship is always there. The parent in such a relationship is committed in principle to the relationship even when facts on the ground stand in its way.

Note that I do not claim that parental love is essential to a child’s flourishing. Studies indicate that some measure of affection, from someone, is necessary for a child to flourish in even the minimal sense of developing basic human capacities within a normal range; and it makes sense to think that parents are the most reliable, though as we know by no means foolproof, sources of such affection. Happily, however, the love of
a nurse or a nanny, or a sibling or a social worker or an extraordinary teacher, may prove enough for a child who has the great misfortune either of losing her parents, or of having parents who fail to love her. Yet, even if the child finds the love that she needs elsewhere, not having parents or having parents who fail to love her is still a great misfortune: there is nothing “happy” about it. For she would nonetheless be deprived of the special goods of a healthy parent-child relationship, goods that would contribute greatly to her welfare or well-being, considerations of flourishing and its proper description apart.

The notion of special goods has been developed by Simon Keller in a discussion of filial duty. In Keller’s terms, what makes special goods “special” in this context is that they are goods that a parent or a child “can receive from no one (or almost no one)” but one another. Special goods are distinguished from generic goods, “which could in principle be received from anyone.” Love is a good that is generic in this sense, but parental love is obviously a good that could not be had from just anyone. Moreover, there are reasons to think that a life would be significantly less rich—more strongly, even significantly impoverished—without the special good of parental love. From the point of view of the child, the special goods of a healthy parent-child relationship include having a person who, having known you intimately since your birth or in any event early childhood, may know, understand, and sympathize with you in ways that others cannot, and indeed in some ways may even know you better than you know yourself; having someone not only who is committed to your well-being, but whose well-being is tightly bound up with yours; having someone who can be counted on to be there for you in a way that you cannot count on most others, not excluding friends and romantic partners and increasingly even spouses; and, in brief, having someone who loves you unconditionally, simply because you are you, that person’s child. Without these special goods and this kind of love, life would be a lonelier, more forbidding undertaking.

I think that we can now return to my question (why would it be wrong, etc.) with a better chance of making headway. Here is a first go at an answer: while making an adoption plan is justifiable when, during a pregnancy, parents realize that they cannot provide for the child as they are obligated to do, for a couple to seek to conceive a child with the idea of giving him or her up simply at will appears to be wrong for two reasons: first, it exposes the child to the risk of potentially debilitating feelings of rejection; second, it treats as a thing of little value something that is potentially of tremendous value and importance to a child, namely, the given or unchosen relationship with his or her birth parents (that is, procreators). To reiterate, the value of such a relationship lies in the fact that it forms a bed for the development of a relationship marked by unconditional love—love that attaches to the child’s being, the sheer fact of his or her existence. In other words, a relationship that is given or
unchosen can serve as the basis for a relationship that can be counted on as given—a relationship offering a child great goods that can scarcely be had from anyone other than a parent.

3. The Transfer Principle

This answer needs, however, some further consideration. To begin with, it bears repeating that adoptive parents, too, can certainly provide a child a relationship that can be counted on as given, and so it seems reasonable to think that adoptive parents can at least minimize the risk of a child's suffering debilitating feelings of rejection. Moreover, though the relationship does not have any biological component and so is not "given" in this sense—the child is not “bone of our bones, flesh of our flesh”—there is an important sense in which, typically, the relationship is nonetheless unchosen. (The terms 'given' and 'unchosen' here diverge.) Putting aside the use of genetic technologies, just as biological parents may choose to seek to have a child, but do not choose the particular child they welcome into the world, adoptive parents choose to seek to have a child, but in the end must simply live with, and discover and come to terms with, the child they welcome into their home. Yes, like biological parents, adoptive parents might know in advance some of a child's gross characteristics, but in fact, at least when the child in question is an infant or very young, they exercise little choice over the nature of the particular child whom they take as their own. Instead, surely the most significant fact about this child for expectant adoptive parents, no less than for expectant biological parents, is simply that he or she is to be theirs, in the profound sense of theirs to rear and raise. Adoptive parents may not be able to see their child as bone of their bones, flesh or their flesh, but they can nonetheless deeply identify with him or her, who after all goes forth into the world by virtue of their labor.

Along these same lines, it should be underscored that what we really value here is the unconditional love of parents for children. Just how a child came to be one's own, which is to say whether through procreation or adoption, appears not all that important (so long as, of course, the child did not become one's own illegally). What is important is that a love develop that is based more on the child's being than on any characteristics that he or she has or will come to have. Such a love, after all, could overcome even confusion at the hospital over whose child is whose, or deception over paternity. In this regard, I think that Paul Lauritzen is right that, “while genetic connection may foster relational bonds, it is the bonds that are crucial, not the genetic ties.” In other words, “it is the ongoing, caring relationship with a child that is the core of responsible parenthood.”

In the end, we need to come to terms with what Tim Bayne calls "the transfer principle," according to which it is permissible to alienate one's parental responsibilities
(over neonates) to another individual (or institution) as long as one has good reason to think that [the individual or institution] will carry out those responsibilities adequately,” without need for further justification, such as that one is mentally or financially incapable of meeting the responsibilities oneself. At the bottom of the transfer principle is the supposition that what procreators owe a child is to see to it that he or she is cared for, not necessarily to care for the child themselves.

I can think of two reasons to be wary of the transfer principle—though note that I do not say to reject it altogether. The first reason is that, while procreators can extract from others the promise of commitment, they cannot extract the thing itself. After all, part of the trauma of adoption is that whether unconditionally loving parents will be found is a matter of chance. Once the child is relinquished, even in open adoptions, how the child is raised is at least largely if not entirely out of the birth parents’ hands. In a word, this objection is epistemic (that is, having to do with the limits of knowledge). What makes it vulnerable, however, is that it is built on a denial of what the transfer principle takes for granted: that one has “good reason” to think that one’s child will be well cared for. Yes, birth parents can never know for sure, but if the adoption is arranged through a public agency, with diligent screening, a thorough home visit, and the supervision of competent social workers, it might be claimed that worry in this regard is unmotivated—worry more “in principle” than rooted in fact.

This defense is strong, but I do not think we should be overly impressed. It is surely correct that a parent who with good reason does not believe him or herself capable of meeting parental obligations does right in surrendering her child to “an organized social scheme of child adoption with an assured historic record of general success.” In such a case, the interests of an existing child speak for taking the chance that his or her life, too, will count among the successes. But it does not follow that this “historic record of general success” would likewise justify the plan of a couple who seek to conceive a child with the idea of giving him or her up (the case, to recall, that got this discussion going). They take a chance that did not need to be taken—more precisely, that the interests of an existing child did not call for—which it is then difficult to see as justifiable. The transfer principle is quite blithe about the likelihood of coming to know that one has “good reason” to entrust others with the demanding, and sometimes draining, responsibilities of raising a child. It might be objected in turn that one cannot be certain about one’s own future commitment to these responsibilities, but this objection seems specious: one can hold oneself accountable in ways that one cannot hold others.

The second reason to be wary of the transfer principle goes deeper. This is that, when all is said and done, the transfer principle does not take into account the value of the given, biological relationship. Again precision is needed: the transfer principle does not take into account the value that the given, biological relationship is accorded in
societies like ours, with roughly our concept and institution of the family, where being bone of another's bones, flesh of another's flesh is a relationship of great significance. (By way of contrast, consider the relationship of simply having the same blood type as another person.) Now, it could well be asked whether the importance of this relationship is merely "socially constructed," and thus relative to this or that society, or universally valid, say a fact of human nature. Imagine, by way of counterexample, a world in which adoption is the norm. Would adopted children experience angst in such a world? I think that the right answer to this question is: we have no idea, for it is not a world with which we are familiar. Not all societies, of course, have or have had the same concept and institution of the family, though all societies have some analogous institution. I am not writing, however, for all times and places. Instead, my concern in this book is with the ethics of the family as we know it—"we" being, roughly, contemporaries who live in societies where the questions that this chapter has been pursuing make sense. In the world that we know, with our kinship structures, the importance of the biological relationship is a matter of course. It is not all right—it is a scandal—for a hospital mistakenly to mix up babies in a nursery. Parents do not want just to go home with a healthy baby; they want to go home with their baby, healthy or not. The questions to ask in this context are just why we accord the biological relationship value and whether we have good reason to do so.

To reiterate, I think that Lauritzen is right that: "while genetic connection may foster relational bonds, it is the bonds that are crucial, not the genetic ties." But the fact that many adopted persons who already have all the genetic information that they want, and also know why their birth parents relinquished them, search for these parents nonetheless ought to give us pause. An adopted person may well enjoy the most secure and happy of relationships with his or her adoptive parents, yet long to know his or her birth parents and feel a profound sense of loss over not having relationships with these parents in his or her life. From this perspective, it seems, so-called responsible child "abandonment" just is not responsible enough.

What it is blind to, I think, is the fact that, similarly to how a child whom one has lost cannot simply be replaced and made up for by a new child, even if that new child turns out to be wonderful in many ways (let us say—absurdly—"better" than the child who was lost), 83 a parent whom one has not known cannot simply be replaced and made up for by a parent who has made one his or her own. In other words, the loss of the relationship with one's birth parents cannot be eliminated by having a loving relationship with adoptive parents. We can acknowledge that a loving relationship with adoptive parents is a great good, and we can recognize that it may well provide consolation; but a unique relationship, because it is a relationship with persons to whom one is uniquely bound (flesh of flesh, bone of bones), has nonetheless been lost. By way of analogy, imagine that one's spouse with whom one has a healthy, loving
relationship decides to leave one, but offers the apology that there is another, in fact much better person eager and willing to take his or her place. Would there be no loss? Clearly there would be: namely, the loss of the relationship, which cannot simply be made up for, since it was a relationship with a particular person, which was itself one of the goods of the relationship.

And yet the argument still cannot be considered closed. For there is no denying that the relationship between spouses is also disanalogous to the relationship between birth parents and a child: to the point for present purposes, a healthy, loving relationship between spouses already is rich, whereas the relationship between birth parents and a child is but potentially rich. Why accord this relationship any value, then, before it apparently becomes . . . well, valuable? Why claim that birth parents may not cast it away as a thing of little or no value when, in fact, it appears not yet to have any value? To the claim that the given, biological relationship ought not to be treated as a thing of little or no value and that one must accordingly have some justification for “abandoning” one’s child to the care of willing and competent others, it could be objected that there are many people with whom one might develop, for example, rich friendships, yet one is not obligated, for this reason, to seek to become friends with any of these people, even if they very much want and would benefit from this relationship themselves. And so the question arises: even acknowledging the special nature of the relationship between procreators and child, what reason is there to think that there is a prima facie, all-things-considered obligation for procreators to develop this relationship? This question bears not only on the ethics of adoption, but on the ethics of gamete donation and surrogacy, as we shall see.

In the end, return to the observation with which this chapter began: one of the things that parents do for children is to presume to bring them into being. This, surely, is no little thing to answer for. For what a presumption! Chapter 2 focuses on how one incurs parental obligations, or what I call there procreative costs, and just what these obligations or costs amount to. After elaborating this account, I circle back to the loose ends of this opening chapter’s argument.
The Ethics of Rationing: Necessity, Politics, and Fairness
The title of this article is meant to encapsulate the three general problems of rationing health care in the U.S.—but I believe it is relevant for other countries as well. Must we ration health care at all and how might it best be done? Can it be done in a fair way? What are the obstacles—political, medical, and public opinion—that stand in the way of rationing? The combination of those questions, each touching on difficult and controversial issues, have made rationing hard to talk about publicly, evaded by politicians, abhorred by the public, and resisted by physicians. I believe that, however difficult, every health care system, however organized, must ration and that its necessity makes it an ethical requirement. There are no theoretical limits to what human beings can want in the name of their health, but there are many practical limits, cost most notably. The issue with rationing is not whether but how.

Hovering in the background is the nature of our health care system and the values that Americans bring with them into discussions of rationing, few of them helpful. Until very recently—and with the obvious exception of the 50 or more million uninsured—most Americans received good and reasonably affordable care provided either through their employer; or if over 65 through the federal government Medicare program, or if poor by state Medicaid programs. That combination began to change with the beginning of the recession in 2008, putting more people’s health care at risk. Steadily, long-term rising costs had become a threat to the entire system, reducing employer-based health care, threatening Medicare and Medicaid, and forcing higher out-of-pocket payments for everyone. The respected and non-partisan Congressional Budget Office put the issue in a direct and succinct way in 2003: “to finance projected spending . . . would require tax increases of an unprecedented magnitude . . . under current policy, future generations will be made worse off by higher taxes or lower benefits” (Congressional Budget Office 2003). If anything, the cost pressures are greater now than when the Congressional Budget Office passed that judgment. Those pressures go against the cultural grain, where expectations about good and indeed always better care (through medical research and technological innovation) have been the norm for many decades.

Defining “Rationing”

While the taxation issue is surely important and will be touched on later, this paper focuses on the cutting of benefits, and particularly that of the most expensive and intimidating program, Medicare. Hardly anyone likes that idea of rationing, even when they agree as a general proposition that it will be necessary. The specter of rationing, and even the open use of the word in the political arena, are the flash point for that
debate.

To begin, let me say what I mean by the word "rationing." I define the word in three categories: There is direct rationing, by which I mean (a) an open and public policy taken by an agency, public or private, to deny needed or desired health care benefits, and (b) to do so in the name of financial stress or on the grounds that the cost of the benefits exceed the value of those benefits. An important distinction is in order here. In the U.S. there is already one longstanding form of direct rationing, that of organs, heart, kidneys, and lungs in particular. In those cases there is an absolute shortage of organs, with the need far exceeding the available organs. Procedures to choose suitable patients are in place to fairly distribute the available organs and will not be further discussed here.

By contrast, what complicates the problem of rationing in the American health care system is that there is no absolute shortage of money for care—we could politically choose to spend unlimited money on health care, and do so at the expense of all other national needs (education, jobs, national defense, among many others). Such spending would make no sense. Because we do not have a single payer government or fully government-financed system as do European countries (what I call closed systems), we are not forced by them to live within a national health care budget. The American system, which I call an open system, has no firm structure for making priority and rationing decisions. Our private insurance sector can set its own rationing rules company by company. In principle, our Medicare program could do so, but has been forbidden by Congress to do that. Our state Medicaid programs for the poor do have to live within a closed budget but any decision to limit a program or treatment is certain to generate a political struggle, well publicized by the media. Sometimes that pressure succeeds in bringing a change, and sometimes not. But supporting Medicaid benefit cuts can also hurt politicians at election time.

The only known instance of direct rationing in the U.S. was in Seattle, Washington, in 1960. At that time, kidney dialysis was a new technology for treating kidney failure, and advances in its use made it possible to keep patients alive for many years. Yet there was a shortage of those devices; not everyone could be saved. The solution to that problem was to establish two committees. One of them was charged with determining the medical criteria for selecting candidates. The task of the other, called an Admissions and Policy Committee, was to choose, as the prominent journalist Shanal Alexander put it, "who shall live and who shall die" (Jonsen 1998).

But direct rationing is not the only kind of rationing. There is also what I call indirect rationing. By that term I mean the use of copayments and deductibles as a way of containing the costs of a health care program. Indirect rationing works by forcing individuals to make financial choices about how much they are willing to spend out-of-pocket for their health care. It is an effective technique for influencing choice
and behavior, leading many to forego treatment or diagnosis in some cases, to avoid filling prescriptions with a high copayment, or to take only half a prescribed drug to hold down their personal costs. The result has the impact on many of discouraging those with poor financial resources from getting needed treatment, making them medically worse off.

Then there is covert rationing, by which I mean decisions made by physicians to withhold potentially beneficial treatments of patients—and to do so by untruthfully telling patients that nothing can be done for them, or simply telling them nothing. There is, that is, no informed patient consent. The most well known form of covert rationing was in the U.K. in the 1960s and 1970s: There should be no kidney dialysis or expensive heart surgery for those over the age of 55. I call that a de facto rule because it was not the result of explicit government regulation but, instead, an informal consensus among physicians forced to make do with tight, fixed budgets, and inadequate funds (Aaron 1984). It seemed self-evident that, given a shortage of money, the most expensive procedures had to be foregone. That practice seems to have faded out in such stark terms by the 1980s, but a distinguished British health policy expert, Rudolf Klein, has observed that it is still going on, though in a more subtle way. As he wrote in 2010:

the most pervasive form of rationing is the least explicit and least visible: rationing by dilution . . . not to order an expensive diagnostic test, or to reduce ward staffing levels in order to balance the budget . . . decisions can be taken in the name of medical discretion and thus be politically invisible.

(Klein 2010: 389)

Obstacles to Rationing

Of all the inflammatory accusations made during the debate about the 2010 Affordable Care Act (ACA), hardly any could top former Vice Presidential candidate Sarah Palin’s claim that the ACA would create “death panels.” There was nothing whatever in the legislation or even the debate leading up to it that involved the use of panels to make difficult individual life and death decisions. But the fact that her phrase caught on in so many sectors and was well publicized by the media reflected a constant theme in the Republican objections to the ACA: That one way or the other, directly or via a slippery slope, medical decisions would be taken out of the hands of doctors and patients and be put in the hands of faceless bureaucrats interested only in the bottom line.

Three forms of resistance to the 2009 ACA legislation became apparent in the run-up to the legislation:

1. Rejection of any form of cost-effectiveness research, or the use of comparative effectiveness research for devising practice guidelines for physicians; even
recommendations to physicians were forbidden.

2. A promised effort by Republicans in the aftermath of the legislation to eliminate the Independent Payment Advisory Board; that Board's task will be to recommend direct across-the-board cuts to the Medicare program if its costs exceed a certain threshold.

3. The further extension of objections (via slippery slope arguments) of that kind to other types of government recommendations, particularly those designed to reduce unnecessary diagnosis and procedures in the name of the quality of care, ostensibly not to control costs but that is thought to be a likely by-product even if not a directly intended result.

More resistance to any kind of rationing came when a 2009 report of the U.S. Preventive Services Task Force (PSTF) recommended that mammography screening of women under the age of 50 should no longer be routinely undertaken (Callahan 2012).

That decision was taken by many critics of the recommendation to be an underhanded and hidden rationing policy to reduce costs. But nothing in the panel's decisions and the reasons given even hinted that its judgment was motivated by cost considerations. But it also fed into a combined physician–industry rejection of government regulation of medical choices. Pressures from industry and physicians were taken to be instrumental in rejecting the first two cost control measures noted above and from physicians in the third case. Why? Industry feared government control of prices of their products and interference with technological innovation. Many physicians feared the replacement of traditional physician discretion and thereby harm to what the American Medical Association called the “sacred doctor–patient relationship.” That view was dominant in the ACA debate and its aftermath.

What to Ration

In response to the great pressure against rationing of the direct kind, health policy experts and Democratic legislators fashioning the ACA bill worked hard to find methods that would in fact cut benefits, but in a way that avoided both the reality and the appearance of rationing (save for the Independent Payment Commission). The most common phrase to describe that effort was “bending the cost curve,” looking for gradual and incremental improvement in reducing cost escalation over a period of years. The bending is to be accomplished in two ways. One way is by bringing greater efficiency to health care by such mechanisms as better coordinated hospital patient care and the bundling of payments, a number of experimental programs to improve the quality of care, improved information technology, and greater support for primary care medicine (shown by evidence to reduce the use of more costly physician specialists)
(Friedberg et al. 2012).

The other method is the reduction of waste, which many experts consider to amount to some 30 percent of costs. Excessive use of expensive diagnostic procedures, poor care of hospital patients resulting in readmissions, and unnecessary bureaucratic procedures top the list of wasteful practices (Berwick and Hackbarth 2012). In the aftermath of the legislation, there have been more claims that the elimination of waste and greater efficiency could itself solve the cost problem (Emanuel 2012). I would only interject here that the call to do just that has been heard for at least 40 years, but without notable success. But it raises no hackles in the medical profession and encounters no patient resistance, making it of great political value.

But if, despite that effort, it is insufficient to control costs, and particularly the high annual overall cost increases (ranging from 3 to 6 percent in recent years), then what? The most common response has been to eliminate diagnostic and therapeutic procedures that are known to have no benefit at all and, beyond that, to go after the "low hanging fruit" where the health gains are minor but come at a high price (itself a form of rationing). No one objects in principle to ridding the system of useless or clearly harmful procedures (even though the ACA legislation bars forcing doctors to do so even in light of good evidence of harm). But the idea of going after the low-hanging fruit runs into trouble in practice. It is the "marginal benefit" issue, where the evidence indicates that little harm (but not no harm) will be done by restricting or discouraging a clinical practice.

Another line of criticism raises a different kind of issue, one going to the heart of technology assessment. Efforts to reduce diagnostic or treatment practices that will be 37 marginal from a population or cost perspective will not necessarily be the case from an individual and physician perspective. And therein lies the moral dilemma of evidence-based medicine: The tension between general statistical evidence based on large groups of patients and the good of individual patients in all their human variety, which can be in conflict. Some small number of women not routinely screened under the age of 50 will come down with breast cancer, and will die of it. Most, but not all, of the screening will be wasteful—and sometimes even harmful—with large amounts of money spent to save a few women, but whose lives are of course important for them and their loved ones. Who, then, is to say that the cost of screening is "not worth it"? In any case, the government backed down in the face of the criticism, saying that doctors and patients only should be the ones to decide on the value of mammography screening. A later report by the PSTF on screening for prostate cancer, also recommending some limits, did not draw a similar response, possibly because there are no organized and outspoken lay advocacy organizations in the same way there are with breast cancer.
Rationing and Chronic Illness

The number of Americans over 65 will grow from 40 million in 2010 to 88 million by 2050. That gain in numbers should be enough to scare anyone. But there is even worse news: The largest proportion of health care costs are incurred by those with one or more chronic illnesses (heart disease, cancer, diabetes, for instance). They are mainly older people, and the fastest growing segment of that cohort are those over 80. The top 1 percent of such patients account for somewhat more than 20 percent of health care costs, and the top 5 percent for almost half of all costs. The average per capita cost of the bottom 50 percent is $236 per capita, the top 5 percent $43,000, and the top 1 percent $90,000 (National Institute for Health Care Management Foundation 2012). It is the success of keeping sick people alive longer than in the past that is at once a great medical triumph and the source of its greatest economic stress. An important part of that problem is costly end-of-life care, not just the few days or weeks while patients are obviously dying but during the often longer preceding time when it is not certain whether a critically ill patient is dying or not. In the latter case they are usually treated vigorously with the hope that they are not at death’s door (Callahan 2012).

The care of the elderly critically ill from chronic diseases, and who may or may not be dying, is an obvious—and also a particularly volatile—place to make budget cuts for the Medicare program. No doubt better coordination of that care and a bundling of costs would be helpful, but it is doubtful that they could make a great cost difference. Moreover, as the endlessly debated issue of end-of-life care has made evident, it is by no means easy at present to do that successfully (Callahan 2011: 115). The main tactics have been to encourage people to have a living will and/or to appoint a surrogate to act on their behalf if they are no longer competent; and these practices that assume that many people will not want aggressive efforts to save their lives if the cost is simply more suffering. Yet no more than an estimated 25 percent of the population has a living will and it is not known how many have appointed a surrogate, despite a 40-year effort to bring that about (Donley and Danis 2011).

Doctors are now better trained to deal with dying patients, but when chronically ill patients are in hospitals the default position in practice is to treat then aggressively. Some 50 percent of the dying are now under the care of hospice programs, but most of them come into those programs much too late, on average a week or two before their 38 deaths. This lag is the result of foot-dragging on the part of doctors, of families who do not want to give up hope, and a result most broadly of a strong resistance to open discussions of death. Worst of all perhaps, the magnitude of the costs of caring for the chronically ill would require rationing on a large scale, and accepting as well the likely fact that some, perhaps many, would die as a result of curtailed treatment. If that meant direct rationing, the political reality in that case would predictably lead to a condemnation of it. At the least, therefore, I surmise,
legislators and health care administrators would find it necessary to obfuscate that reality, either through shifting more costs to patients or quietly encouraging covert rationing.

If chronic illness in general is an obvious target for rationing, close on its heels (though of much lower aggregate costs) are the high costs of many new cancer drugs and expensive heart disease procedures. The cancer drugs can cost anywhere from $50,000 to $320,000 (Sullivan et al. 2011). In most cases their added survival value is relatively slight, from a few days to a few weeks only, a marginal benefit only from a cost perspective. Yet they are also a perfect example of an imbalance between individual patient needs or desires and their burden on the health care system. Their seemingly small benefit is, in the eyes of many patients and their doctors, well worth the cost—and Medicare cannot, by law, refuse coverage on the grounds of cost alone. There have been no successful efforts over the years to change that law (Fox 2005).

**Modes of Rationing**

I earlier defined three kinds of rationing: Direct, indirect, and covert. I want to concentrate my attention on direct rationing, but will say a few things about indirect and covert rationing. Indirect rationing by the use of copayments and deductibles has been employed by Medicare and private insurers as a way of lowering their own costs by shifting them to patients. The Medicare program costs its beneficiaries an average of $3,000–5,000 per year in out-of-pocket costs and up to $10,000 in some cases (Komisar et al. 2012: 4). This can be a large burden on those with poor income security, leading them to cut doctor visits and to either not fill prescriptions at all or take less than the recommended dosage to delay getting refills. It is a technique which works to hold down Medicare costs, but comes at the price of increased health risk for vulnerable patients. As for covert rationing, that seems to be undertaken when there is a shortage of resources in systems with constraining budgets, and political realities make it difficult for health care administrators to engage in open and direct rationing. That poses an obvious problem of justice for democratic societies, leaving patients at the mercy of ad hoc invisible judgments and the perhaps idiosyncratic values of the physicians who make them.

If there has been any bioethics consensus about direct health care rationing, it is due to the philosopher Norman Daniels and his concept of “accountability for reasonableness” (Daniels 2008: 274). The concept draws upon the work of the late political philosopher John Rawls who stressed the importance of public visibility of decisions taken in the name of justice. Daniels amplifies that premise by specifying that principle and three others as constituting reasonableness: Decisions and their rationales must be publicly accessible; they must appeal to “evidence, reasons and
principles that are accepted as relevant by 'fair minded' people who are disposed to finding mutually justifiable terms of cooperation”; they must be open to appeals for revision; and there must be “voluntary or by public regulation of the process to ensure that [the other] conditions are met” (Daniels 2008: 118). Closely related to that set of principles is the work of Leonard Fleck who speaks in terms of “democratic deliberation.” That deliberation encompasses “constitutional principles of health care justice, such as a principle of equality, of liberty, of fair opportunity of opportunity, a principle of publicity, respect for persons, liberal neutrality, and reciprocity” (Fleck 2009: 184).

There is much that could be commented on in the valuable work of Daniels and Fleck, but I want to single out the ideas of "publicly accessible reasons" and "publicity." I will do this in the context of empowering public bodies to make overt rationing decisions, and particularly in a political setting beset by sharp ideological divisions. Sarah Palin's emotionally potent attack on "death panels" reflects that reality, but there are two other interesting cases: One in Seattle and the British National Health Service (NHS) means of controlling costs.

I noted above that a kidney dialysis shortage in Seattle led to the establishment of a committee to decide who would have access to the machine. It ran into considerable criticism. It was for one thing an anonymous committee, and for another its criterion for decision-making was that of "social worth." It is understandable that it was anonymous, protecting the committee members from direct attack for their decisions, but then of course its decisions did not meet the publicity and openness standard. But could the committee have proceeded successfully in any other way? There is no way of answering that question. In any event, Dr Belding Scribner, a research leader on dialysis, later said that "we had been naive" to think that what seemed to be a "reasonable and simple solution" of "letting a committee of responsible members of the community choose patients" would evoke a “serious storm of criticism” (Jonsen 1998: 211). Moreover, it was reported that the committee itself had great difficulty in making decisions: Just what is "social worth” anyway? Some bioethicists entered the fray, with some opting for a simple lottery as the fairest method of choosing, and others supporting a social worth standard. The Seattle experience is not one that other countries are likely to repeat.

The experience in the U.K. of the National Institute for Health and Care Excellence (NICE), established to give advice to the NHS on allowing new (and sometimes old) technologies to be paid for by the government, offers a cautionary tale. One of the main economic tools used by NICE is the use of quality-adjusted life years (QALYs). Since there is another paper in this volume on QALYs (see Chapter 4 in this volume), I will not spell out how it works. But I will note that the decisions of NICE do not escape the eyes of the media. In a few cases, particularly with expensive cancer
drugs, the media often turn them into public controversies, typically interviewing the usually anguished cancer victims and their families who might be denied the drugs. In some cases, the NHS backs down or agrees to further studies; and in others the complaints are taken to court (Steinbrook 2008).

Publicity, in a word, is sufficient to create problems for the NHS, which makes the final decision. One criticism of NICE, ironically, is that it does not encompass the views of individual patients, suggesting that it should find ways of doing so—a path that could lead back to individual decision procedures reminiscent of the U.S. Seattle committee (Speight and Reaney 2009). Interestingly, however, NICE approves new therapies in the large majority of cases, thus often increasing costs. Its approvals are automatically accepted by the NHS while its disapprovals are treated as recommendations only, and turn out to be little more than 10 percent of its decisions (Steinbrook 2008).

It is probably no accident that it is hard to find instances anywhere in the world where rationing decision committees have been used and actually adopted the rigorous standards proposed by Daniels and Fleck. Can there be effective and politically acceptable “democratic deliberation” on volatile matters of life and death, with publicly known winners and losers? I have come to doubt it. The fact that Republicans have particularly targeted the Independent Payment Commission, with its capacity for making blunt cuts in the annual Medicare budget, conveys a profound unwillingness to give government agencies that kind of rationing power. And even some of those who favor benefit cuts resist such blunt cuts on the grounds that they could well be unfair to many, systematically indifferent to their variable patient impact. It is hard to imagine, however, what kind of deliberation and decision procedures would work to deal fairly with variable impacts. They would surely be complicated and inherently contentious.

Is Open and Fair Rationing Possible?

I have not painted a bright future for the possibility of open and fair rationing. That the U.K. is now still seeing the covert kind reflects how difficult it can be in practice to make it an open and transparent process. A 2007 study of rationing in four European countries—the U.K., Italy, Norway, Switzerland—found that covert rationing is common, and that the reasons can include patient age and cognitive impairment (Hurst et al. 2007). My own experience over many years in questioning European physicians about rationing in their countries is that I always get vague answers, suggesting that it is a topic that neither they, nor their legislators, like to talk about publicly.

Some years ago two prominent legal scholars wrote a book called Tragic Choices, arguing that some delicate and difficult problems in public policy simply could not be treated in a fully open way (Calabresi and Bobbit 1978). They got plenty of
criticism for the likely unfairness and other drawbacks of veiled or covert decisions. But they had a point, at least if the experience with open health care rationing shows how hard it is to implement fair and publicly accessible decision-making procedures. Accountability for reasonableness, however theoretically appealing it might be for policy making, may simply be unworkable for health care rationing.

Where might we better look? My own view, in light of that pessimistic judgment, is that modern medicine has created background conditions for the delivery of health care that are the ultimate causes of the cost problems—now experienced by every industrialized country regardless of how its health care system is organized (and they are all different). Some do better than others, and the U.S. has the worst problems, but all have annual health care increases exceeding the annual growth of their gross domestic product. That is the standard most countries aim for, and none succeed. For all countries, rising costs are a source of anxiety and reform efforts. Steadily rising health care costs are simply not sustainable in the long run. Tinkering with the delivery mechanisms of health care with overt rationing is not likely to make a great difference in a way that is politically tolerable.

**Changing the Goals of Medicine**

There are three main drivers of health care costs, affecting every country’s health care system: Aging societies, new and intensified use of medical technologies, and public demand and expectations. Behind all three of them is a model and vision of medicine more or less guaranteed to drive up costs. I call it a progress and innovation model. Its aim everywhere is more and better health for everyone. Medical progress as an ideal has no finite goals: It always seeks more. Technological innovation, its main tool and knowing no inherent limits, is always an open and beckoning frontier with endless vistas of possibility. Patients and would-be patients have come to embrace and expect that kind of medicine. Yet the net result has not been to come anywhere near the conquest of disease. Instead that model has given us a medicine that offers few definitive cures, but can expensively prolong dying bodies, especially from the chronic diseases of aging. What I call “the great tradeoff” is a mixed blessing: We live with much longer lives than our ancestors but with much greater illness in old age; and we are subject to extended suffering, and high costs.

The underlying medical model must be changed if an affordable and sustainable medicine and health care is to be achieved and the need to ration minimized. An important part of that goal will be to understand that we all die. The culturally ingrained medical effort to fight endlessly against death is a losing cause. An aging marked by an extended life with painful and crippling disease is hardly a benefit. To be even more specific, I believe that by 80, people will have achieved most that a
human life can give us (if not necessarily everything one might desire): Education, work, travel, and family, for instance.

The goal of medicine should be to keep us alive and in good shape until 80 but should be under no obligation to help us become indefinitely older. I say this as one who is 83. I trust I will be missed when I die by my family and friends, but the country will be able to manage well enough without me. Others will take my place, as they have always done in the passing of the generations.

I propose a model for the future of medicine and the health care system to go with it. Imagine a pyramid. At the broadest bottom level is public health (e.g., sanitation, disease surveillance, prevention), and efforts to improve the socio-economic determinants of good health (income, education, jobs, public and industrial safety). At the next level is primary and emergency care medicine. Still one level up is general hospital care, and at the level above that advanced and ICU care (but the latter only for those who have a reasonably good prognosis). At the top would be the most expensive technological care (e.g., expensive cancer and heart procedures) to be allowed only with an exceptionally good prognosis. The aim of the health care system would be to make care at the top of the pyramid relatively hard to get, aiming to push everyone down the pyramid as far as possible, from the higher to the lower levels.

To be sure, that would be a rationing scheme, but one that will be increasingly plausible if it set more finite goals for medicine, aiming to get a better balance between care and cure, and bringing about a fundamental change in the way people think about health care. It is indeed utopian, but I have provided a variety of reasons why the most conventional ideas about rationing will fail, mainly because rationing is exceedingly hard and filled with traps of one kind or another. Health care systems can attempt to ration health care, but that task becomes insuperable if built on an underlying model of medical progress that has limitless research and curative goals.

What I can imagine emerging is a hybrid system of rationing. It would combine four elements. First, cost-effectiveness and comparative-effectiveness research would be used to generate reliable data assessing the efficacy of technologies, new and old. Second, with that data in hand the government would then lay down some recommended rules and guidelines of a general kind for the treatment of various costly conditions, those at or near the top of the pyramid. Research on prognosis, already underway, would be improved so that it would have reliability with chronically ill patients (Smith 2011; Yourman et al. 2012). Fourth, information technology would be used to keep track of doctor–patient decisions (or at least a good sample of them) in light of the general government guidelines. The assessment standards now used by the U.S. PSTF offer a good model for doing that (categorizing different levels of technology effectiveness).

Adjustments would be made if it became clear that the recommended
guidelines were not effective or widely ignored. The principles of "Accountability for Reasonableness" and those offered by Leonard Fleck could be used at the second stage, and that would have to be the work of a committee. But fifth, in taking account of the nature of cost-effectiveness and comparative-effectiveness research, which of necessity is based on population studies, and that of the individual differences among patients, some degree of physician discretion and judgment will in the end always be necessary. And their experience in trying to follow the guidelines can be used to change or improve them.

In sum, this hybrid model is meant to deal with the most common challenge to rationing schemes: That of finding a middle ground between (a) fear of the impersonality and insensitivity to individual patient differences and physician judgments that are widely thought to go with government domination of medical practice, and yet (b) the need to have some central government agency or committee assess the evidence, balance cost benefits and formulate recommended, not commanded, national standards. Each side is given a role, and each side interacts with the other. But the key necessity to make that strategy feasible is that of a finite model of medicine, one that will change the way the goals of medicine are understood in the future.
CHAPTER 5

Justice
Introduction

Justice is something every child seems to know about from an early age. How often do parents hear the complaint ‘But that isn’t fair!’ Justice, seen as ‘fairness’, means that everyone should be treated equally, unless there are differences between them to justify unequal treatment. So, when children say, ‘But that’s not fair!’ they might be complaining about unequal shares of a treat, or, perhaps, being made to go to bed earlier than other children of the same age. Of course, these are trivial examples, but questions of equal treatment and fair shares are very serious in the adult world, and relate not only to shares of material resources, such as food and water, or land, or income, but also to equality in the possession of basic human rights – freedom from unjustified criminal proceedings, such as unlawful arrest and detention, the right to vote and to be given equal opportunities for participation in society, and fair access to education, employment and health care.

We can distinguish between different spheres of justice: criminal justice, which ensures fairness and impartiality in defining and dealing with crimes and in punishing offenders; civil justice, which arbitrates in disputes between people or institutions on such matters as finance, property and contracts; social justice, which seeks a balance between the rights of the individual and the welfare of society as a whole; and distributive justice, which deals with the fair distribution of burdens and benefits in society. In this chapter I will be looking at only the last two types, social justice and distributive justice, as these relate to the area of bioethics. So, first, I shall look at the dilemmas of public health ethics, where we need to balance the good of society with the freedom of the individual, then I shall discuss three key issues in distributive justice in bioethics: access to health care; global inequities in health; and global survival.

Public Health Ethics

We can date public health ethics back to nineteenth-century England, when massive outbreaks of cholera were decimating the population and causing fear and alarm in all the major cities, most especially London. The popular medical theory of the time was that the disease was caused by ‘bad air’ or a ‘noxious miasma’. In fact, cholera is spread by insanitary conditions and, in particular, contaminated drinking water. This was clearly established by a physician, John Snow, who discovered that the highest incidence of the disease in the Soho district of London was in an area round the water pump in Broad Street. Snow was able to halt the spread of the disease by the simple expedient of having the handle of the pump removed!

This combination of the scientific study of patterns of disease and its
associations with other social factors (now called epidemiology), allied to decisive social action, is the concern of public health ethics. It explores the ethical aspects of the policies and programmes that can both prevent disease and promote health in the population as a whole, possibly involving restricting the freedom of individuals for the public good. We can look at two examples of this in current health and social policies. Firstly, there is the field of preventive medicine, which devises measures to prevent or control disease. Secondly, there is the field of health promotion, which uses various means to encourage healthier life styles through persuasion, education and legislation.

**Preventative Medicine**

Preventive medicine uses various measures to attempt to prevent or control the spread of disease. These are: screening; vaccination and immunization; and compulsory notification of disease and controls on the movement of infected people.

**Screening**

Screening consists in administering tests to people to see if they either have or are in danger of developing a disease, or are in danger of passing on a disease to their children. It can be done prenatally (for example, to detect whether a foetus is affected by Down syndrome or other genetic defects), postnataally (a good example is the test on newborn babies for PKU – Phenylketonuria, a rare but very serious disease), or to young people and adults (for example, to test for sexually transmitted infections, or susceptibility to breast cancer, or for the gene that would result in their children developing cystic fibrosis). The ethical problems here are to do with the accuracy of the tests and with whether they are optional or mandatory. In the case of screening for PKU, many countries and states make it compulsory for all babies, since it can be treated effectively by dietary restrictions, but will lead to severe brain damage and mental retardation if untreated. But what about tests where there could be ‘false positives’, meaning that the person will not in fact develop the condition, or ‘false negatives’, when the person is wrongly reassured that they are clear, when in fact the disease has not been detected? The problem of inaccurate predictions means that most screening should be optional, with the person (or the legal guardian) given full information about the strength of the prediction and about what, if anything, can be done if the test is positive.

**Vaccination and Immunization**

Vaccines contain a dead or live but weakened germ that can cause a particular disease,
like tetanus or smallpox. When we are given a vaccine, our body immediately produces antibodies against the foreign body. Immunization occurs when our body has developed immunity to it, either because we have been vaccinated or because we have already contracted the disease and recovered from it. Vaccination does *not* guarantee immunity. Natural immunity happens only after one has recovered from the actual disease, but for most people vaccination is a very effective way of preventing them from developing the full-blown illness, and it has resulted in a dramatic reduction in infectious diseases (at least in the wealthier nations of the world). Another important outcome of widespread vaccination is that it reduces the prevalence of the disease in whole populations (producing what is called ‘herd immunity’), thus reducing the risk of anyone in that group becoming infected, even if they are not immune.

As with screening, the main ethical issue is whether there should be a mandatory or a voluntary policy for vaccinating children against the most serious and common diseases (for example measles, mumps and rubella, the three diseases prevented by the MMR vaccination). There may be some discomfort for the individual child, and, in very rare cases, possibly some serious side-effects, but if too many parents refuse to have their children vaccinated the disease will spread and herd immunity will be lost. Thus, there is a clear conflict between individual choice and community benefit. So-called ‘free riders’, who refuse to have their children undergo any vaccination risk, but then rely on most parents agreeing so that their own child will be protected by herd immunity, seem to lack a social conscience. Moreover, if their example is widely followed they do not in fact protect their child, since, as we have seen, herd immunity will be compromised! Despite this risk, most countries do not enforce vaccinations, but rely instead on indirect means of getting parents to comply, for example, by making it a condition of school entry.

*Pandemic Controls*

Diseases do not respect national boundaries, and so the spread of serious diseases worldwide (pandemics, like the SARS outbreak) will often mean putting major restrictions on individual liberty. At the more moderate end of these controls are temperature screening and other health checks on travellers, which can result in their being refused permission to travel. At the most extreme end are measures to isolate infectious individuals, such as home quarantine or even isolation in a special facility until they are no longer a risk to others. Another measure is to compel health care practitioners to notify the authorities of the details of all affected patients (thus breaching confidentiality) so that, if need be, these people’s freedom can be restricted so long as they are infectious.

In all these examples the requirements of preventive medicine illustrate the
limitations of making individual autonomy the only norm in bioethics. There are clear examples of when potential harm to others will require compulsory measures to control the actions of those who may fail to act responsibly. The dilemma, however, is to know how high the likelihood of harm should be in order trigger such restrictions, and what degree of restriction on freedom is justified by it. Proportionality between harm and benefit must be maintained, so that panic over the spread of disease does not result in unfair restrictions on individuals.

**Health Promotion**

The same tension between freedom and control can be seen in efforts to promote healthier behaviour in individuals and populations. An extreme example of coercion in order to achieve social goals is the 'one child' policy in the People's Republic of China. The policy prohibits certain groups (ethnic Han Chinese living in urban areas) from having more than one child, in order to slow down the population growth in the world's most highly populated nation. The policy has reduced the rate of growth, but has also resulted in an imbalance between males and females because of the social preference for boys, and it is also reported to have led to forced abortions and sterilizations, and even to infanticide. However, there are other examples, in more liberal countries, of coercive measures to achieve health goals, notably laws relating to car seat belts and to motorcycle and bicycle helmets. In these cases, restrictions on individual behaviour can be very effective in reducing the seriousness of injuries from road traffic accidents, thus saving health care costs.

In a grey area between compulsion and individual choice are uses of advertising techniques to warn people of risks to their health. Notable examples have been the Australian government's 'grim reaper' advertisements, warning people of the lethal effects of AIDS resulting from unprotected sex; and graphic images on cigarette packets (in some but by no means all countries) showing the range of diseases and disfigurements caused by smoking. Although such health promotion methods are not coercive, they do seek to change behaviour by the same kind of powerfully persuasive methods that are used to sell products (lethal or otherwise). So it could be argued that people are not given a chance to make a considered decision. But, of course, the same can be said of any effective marketing, since it rarely, if ever, appeals merely to rational choice. The founder of the Salvation Army, General Booth, is reported to have said, 'Why should the devil have all the best tunes?' and the same might be said by those trying to persuade people to protect their own health. If better health is the outcome, then maybe the methods employed are justified. Other methods of health promotion can be described as 'health education,' since these rely on factual evidence and rational argument to persuade people to change their unhealthy habits. A good example of this
is information on healthy and unhealthy diets and clear labelling on food packets.

We can see, then, that social justice requires that we either persuade or compel people to act for the good of all (and often at the same time also for their own good). If we want to retain the priority of liberty in ethics, then the best way of achieving this would be to create a civil society in which people were committed to the welfare of all, not just to their individual advantage. The dilemma, however, is that this may not be easily achievable, and so we may need to use the force of advertising or of the law to ensure a maximization of the public good.

**Fair Access and the Paradox of Health Care**

We turn now to a different realm of justice, distributive justice, in which we are concerned not with influencing people’s behaviour for the common good, but with ensuring that they get a fair share of that good. On the basis of an understanding of distributive justice as fairness in the distribution of rights and benefits, we can see why discrimination in access to health care in terms of gender or sexual orientation, ethnicity, age, religion, political beliefs or social class is – on the face of it at least – unjust. (We would need to find very good reasons for showing why these differences in any way justified unequal treatment.) However, deciding what is fair is not always as easy as such blatant examples of racism or sexism might suggest. Fairness can in some circumstances mean treating people unequally. The Greek philosopher Aristotle said that ‘We must treat equals equally, but unequals unequally.’ Another way of putting this is to say that we should treat people in a way that is proportionate to their relevant differences. This can be described as equitable treatment, rather than equal treatment.

But what are the relevant differences? What kind of differences justify unequal treatment in health care? A person’s age is an obvious example: we do not expect young children to be able to look after themselves properly without help; and the same may apply to very elderly people, if they lose some of their mental or physical capacities. There also are many examples where the lottery of life has given people an unequal share of ill-health, perhaps through inherited physical or mental disabilities, or as the result of catastrophic illness or accidents. These examples give us a clue about how we might understand distributive justice in health care. It will be achieved by paying attention to the wide differences in the needs and capacities of people. These differences can be seen as ethically relevant ones, possibly justifying unequal treatment; and we can go further by employing a positive theory of justice as fairness, which would seek not just to meet needs, but to alleviate people’s needs and to restore or improve their capacities.

However, achieving fairness in the distribution of the means to health is made still harder by our uncertainty in knowing how to define health. As we noted in Chapter
1, when the WHO was founded, it adopted a highly idealistic definition of health: ‘Health is a state of complete physical, mental and social well-being, not merely negatively as the absence of disease or infirmity’ (World Health Organization, 1948). This definition has often been criticized because it seems impossible to achieve, yet the WHO has never changed it. Clearly, no one is likely to attain such a complete state of well-being, and many will fall very far short of it. However, it can be seen as a kind of vision to aspire to, a reminder that too narrow a definition, for example, one which focuses on what medical treatment might achieve, can miss out other critical factors in ensuring health, such as the social and physical conditions in which people live and work. So, treating people fairly will mean not only giving them equal access to health care (though this is obviously important), but also creating and sustaining an environment in which people can flourish physically, mentally and socially.

But in trying to achieve this worthy goal of health for all, we run into another problem: modern medicine has been a victim of its own success. In higher-income countries, where infant mortality has been dramatically reduced and life expectancy has been raised well past ‘three score years and ten,’ the costs of health care continue to spiral upwards, making it increasingly hard for individuals, insurers or governments to foot the bill. This has been called the ‘paradox of health care’ – if it is successful, the demand for it, instead of decreasing, continues to rise, ensuring that demand will always outstrip supply. This is due to a number of factors. Firstly, we now have the ability to extend the life expectancy of people with conditions which would have been almost immediately fatal in the past – organ transplantation provides a good example of this, and another example would be our ability to keep premature infants alive at earlier and earlier stages. This leads to raised expectations about what medicine can achieve, and so to a constantly increasing demand for highly expensive technical solutions to health problems. Secondly, as people live longer they become prone to a wide range of chronic diseases which are not open to cure but, rather, require expensive long-term treatment, often with an array of costly drugs. Thirdly, the increasing proportion of elderly people results is a higher incidence of cognitive impairments, such as Alzheimer’s disease, and so creates an escalating demand for support services. Fourthly, although the major infectious diseases may have been eradicated in higher-income societies, their place has been taken by the ‘diseases of affluence’, many of them (such as diabetes and heart disease) provoked by rising levels of obesity. The resulting paradox is that, rather than making people healthier and more content with their lives, effective health care can make them less satisfied and less healthy! Moreover, this discontentment can lead to further behaviour hazardous to health, such as alcohol and drug abuse, smoking and unprotected casual sex.

Determining Fair Shares

Since it seems inevitable that the demand for health care will always exceed the
supply, it becomes necessary to think of ways in which the available resources can be fairly distributed. We can look at this on three levels: macro-, meso- and micro-allocation. The ‘macro’ level is concerned with how much of a country’s total financial resource (its Gross Domestic Product (GDP)) is devoted to health, as compared with, say, education or defence. The ‘meso’ level is concerned with how the total resources available for health are distributed among different services or patient groups (for example, on acute hospitals as compared with on long-term care). The ‘micro’ level (sometimes called ‘health care rationing’) is concerned with who gets a given treatment when there is not enough to give it to everyone who is seeking it. I shall discuss all three levels, but spend most time on the third one, the rationing debate.

**What Price Health?**

There is a huge diversity in the percentage of GDP spent on health care across the nations of the world. The highest spender is the USA, for which the latest figure is 18 per cent. This compares with as little as 3 per cent or less spent in the poorest nations. Moreover, even though the USA is the highest spender on health care, it achieves poorer health outcomes than other countries with a lower spend. The American infant mortality rate is higher than in 50 other countries, and life expectancy is at only the 28th rank overall (OECD, 2011). Thus we can see that equitable health outcomes will not be achieved merely by spending more money on health care. There are a number of reasons for this. The first is that it is not just a matter of how much money is spent, but of how fairly it is distributed and how efficiently it is used. In countries which do not provide universal health care, like the USA, the large number of people without insurance (or with inadequate cover) avoid seeking help until a crisis strikes them, by which time they are much sicker and likely to die earlier than would have been the case if they had received care sooner. (One clear example of this is the lack of adequate prenatal care for poorer women, resulting in higher infant and maternal mortality.) A second reason is that systems which provide reimbursement to health care practitioners according to the services, treatments and tests provided give a perverse incentive both to do unnecessary tests and to over-treat with expensive drugs and procedures. (For example, there is an over-provision of magnetic resonance imaging scanners in the USA, with unnecessary usage needed to recoup the costs of investment in them. Unnecessary surgical procedures, with an associated mortality rate now much higher than that for childbirth, is another major area of concern (Gawande, 2011).) A third reason for the poor return from the high spending on health care in some countries is that health status and mortality rates are not dependent only on the provision of health care (even when it is efficient and effective). The most powerful
causal factor in ill-health is poverty and its associated problems of inadequate housing, unsafe neighbourhoods, poor diet leading to malnutrition or obesity, chronic unemployment and low educational attainment. These factors are very obvious in resource-poor countries with unsafe or insufficient water, inadequate sanitation, periodic famine and violent conflicts, but in the higher-income countries the greatest health problems and shortest life expectancy also relate directly to degrees of social deprivation. Thus the price of health is not simply the amount spent (efficiently or otherwise) on health care. To achieve good outcomes in health and life expectancy, governments have to look at the whole social fabric of their country, at its welfare, housing, education and income-distribution policies as well as the efficiency and effectiveness of its health care provision and effective health education.

The Inverse Care Law

This leads us to the ‘meso’ level of health care allocation, since the effectiveness of health care interventions will depend not only on the total amount spent, but on the way that the total sum is distributed between different groups of people and between different types of service. I can illustrate this with a story of a village on the cliff edge. This village (so the story goes) was very picturesque, with a cosy village pub (not too constrained by licensing hours) and a wonderful view across the ocean from the cliff’s edge. The only downside was that in the cold and dark winter evenings some of the villagers (after, perhaps, too jolly a time in the pub) tended to lose their way home and, straying too close to the edge of the cliff, sometimes fell over, plunging down to the rocks below and getting seriously, sometimes fatally, injured. These accidents were becoming so common that the villagers resolved to raise money for an ambulance station at the foot of the cliff with a rescue helicopter ready to get the injured rapidly to the hospital. Luckily, one of the villagers had a better (and much less costly) idea – why not erect a fence along the top of the cliff and provide better lighting in the village? (And, maybe also, why not encourage people to drink more moderately?)

This story is a parable illustrating one of the problems in health care allocation at the ‘meso’ level. There are very few examples of really effective health care planning that puts ‘fences at the top of the cliff’, as opposed to investing in the highly costly rescue services at the cliff bottom. The acute sector of medical care tends to absorb a massive proportion of the overall budget, and this is true even in low-income countries, where the obvious priority should be on community services and the provision of healthy living conditions and health education. To some extent this is quite understandable, since prevention is often much harder to achieve than crisis intervention after a potentially fatal event. Altering people’s behaviour (ensuring moderate drinking in the pub) is slow and often patchy in its effects – good examples
of this problem (discussed earlier in this chapter) would be succeeding in persuading people to avoid ‘junk food’ or to give up smoking. It is also very hard to curb spending in the acute sector. What has been called ‘shroud waving’ often makes this politically impossible. When advocates for acute services warn of more deaths unless the money is spent, neither politicians nor the electorate are likely to support allocating the funds elsewhere. Yet, if we think in terms of justice as fairness, then this seems an unfair distribution of resources, since some people who could have been spared major illness or suffering will have to endure it because all the priority has been put on rescue medicine.

Another dimension of this problem relates to the commercial interests behind the promotion of health-hazardous products. Tighter control of the food industry so as to ban the unhealthy ingredients in popular and cheap food, or requiring the drinks industry to use minimum pricing so as to reduce excessive drinking would both be effective ‘fences’. However, powerful lobbying by these industries makes this very difficult to achieve in some countries. Another example of the struggle between disease-prevention efforts and commercial interests is the long international saga over restrictions on cigarette packaging and advertising. It is only very recently that just one country, Australia, has managed to make it mandatory for plain packaging with accompanying graphic images of the detrimental effects of cigarette smoking to be used on all brands.

As well as dilemmas in the fair allocation of resources between types of health care intervention, there is an even more complex problem – how do we make a fair comparison between one group of patients and another, whose needs may be very different? For example, if we had a limited amount of money to spend at any given time, should it be spent on better conditions for the residential care of people suffering from dementia or on some high cost treatment for cancer? The former might give a larger number of people a more personal and dignified form of caring, but the latter could prolong the survival of (perhaps) a smaller number of people. This kind of allocation dilemma forces us to consider how we can devise a workable theory of justice in health care, and I shall return to this below, but in the meantime we can note how hard it is to compare needs of quite different kinds. Who is to say which is the more valuable: an improved quality of what are already quite limited lives, or more months (or maybe even years) of survival with a terminal illness? We badly need some kind of sophisticated theory of justice to sort this problem out. (Watch this space!)

A third problem in allocation at the ‘meso’ level relates to what the British writer Tudor Hart called the ‘inverse care law’. He stated it as follows: ‘the availability of good medical care tends to vary inversely with the need of the population served’ (Hart, 1971, p. 405). Another term for this problem is ‘post code rationing’ (in America it would be ‘zip code’). In this case we have the unfairness of the fact that the same needs are
being met unequally, because of an ethically irrelevant difference, namely where people live. This difference is of course true on a global scale, as we shall see later, but even in developed countries with universal health care, like the UK, there continue to be problems of inconsistency in health care provision. This problem is partly because health care practitioners prefer to work in socially desirable areas, with a patient population who are more likely to look after their own health as much as they can and who are educated and articulate. (Sometimes people in deprived areas with multiple problems are described, unkindly, as ‘heartsink patients.’) But a second problem has to do not with the availability of services but with their perceived accessibility and relevance. People can be caught in such a circle of deprivation that they tend to have lost trust in professional helpers and so avoid seeking help. Thus, the issue of access to services (in a social and psychological sense) becomes crucial. This means that any theory of justice in health care must look not only at need, but also at capacity to benefit.

**Death by Numbers - Rationing Health Care**

At the ‘micro’ level there is the problem of choosing who is to receive a given treatment when there are not the resources to treat everyone. A sign outside a garage is reported to have read: ‘We can do good repairs, quick repairs and cheap repairs. Customers can have any two of these, but not all three.’ In other words, if the repair is good and quick, it won’t be cheap; if it’s quick and cheap, it won’t be good; and if it’s good and cheap, it won’t be quick! When we consider micro-allocation (usually called health care rationing) we run into a similar set of choices – good, quick or cheap? Examples of such rationing dilemmas are deciding who gets a kidney transplant when there are not enough available organs for everyone; deciding who should get priority for hip operations that will restore mobility, or cataract operations that will improve vision; providing very high-cost medication that will slow down the onset of dementia, when the budget is insufficient to treat everyone for whom it could be effective; allocating places in longterm care facilities so as to relieve the burden on families; and determining who should remain in an intensive care unit, when laces are limited and fresh emergency admissions are predicted.

If we think of the notice in the garage, we recognize that, ideally, we want to give everyone treatment that is quick and good, but the problem in doing this is that we cannot afford that for everyone. So, often, at least in publicly funded provision, the cheap and good, but not quick, option is employed. In other words, a waiting list is used to ration the resource, with some people having to wait for the ‘repair.’ But this raises three ethical problems: dealing with the problem of queue jumping; deciding the criteria for the length of wait; and the risk of what I have called ‘death by numbers,’ in
other words, our waiting criteria may mean that some people will die before they reach the top of the queue. I shall discuss these three issues in relation to one of the problems in rationing: the allocation of kidneys for transplantation.

Queue Jumping

If we think again of the notice in the garage, we see that wealthier people could take the option of ‘good, quick, but not cheap’, and so purchase the first-available compatible kidney (if it were legal to do this). Yet this seems unjust for at least two reasons. The first is that we do not see being wealthy as giving a person a greater right to life and health. It may be true, in fact, that richer people live longer because they can afford the kind of life style and services that promote longevity, but this does not mean that it is fair that they have this advantage. Health is not a commodity, like luxury goods available to anyone who can afford the price. Instead, health is so central to human well-being that we believe everyone (in an ideal world) should have an equal amount of it. Secondly, if ability to pay is to be the main criterion, then it seems likely that those people who could benefit more from getting the kidney will be deprived of it, since the available supply will be used up by less-sick rich people. Again this seems unfair, since ability to benefit seems to be a morally relevant difference between people, while ability to pay does not. This second objection leads us to the question of what are the right criteria for allocating places in the queue.

Who Comes First?

Imagine three people, all of whom would be medically suitable recipients of the one available kidney. The first is a young man in his early twenties. He is currently on renal dialysis, which restricts his ability to continue with some sports he enjoys and also limits his ability to get a job. He has no dependents and lives at home with his parents. The second is a married woman with two young children. She has been on dialysis longer than the first candidate and her medical condition may reduce her chances of the transplant’s being an effective solution in the long term. The third is a man in his late fifties who is divorced and sees his grown up children only rarely. He has been on dialysis for several years and his chances of surviving much longer on it are poor, partly because he does not comply well with the treatment requirements, such as dietary restrictions and alcohol intake. However, a transplant is likely to give him more years of life and, without it, he will die soon. So who should get the kidney?

Some writers have suggested that we can solve dilemmas like this by a calculation of the number of years of life to be gained by the intervention multiplied by the fraction of quality of those years (where 1 is full quality and 0 is no quality). These
are known as Quality Adjusted Life Years (QALYs). On this calculation the young man would probably get the transplant, since, as the youngest, he has the chance of survival for many years and his medical condition is such that, once off dialysis, he will probably be able to lead an active and productive life. The woman, on the other hand, has fewer years of life ahead of her and, as the transplant may be less likely to be effective, her QALY score will be further reduced. At the end of the queue is the older man, since he has fewer years again and his failures to comply may lead to problems with the transplant also. Yet, without the transplant he is almost sure to die!

Who Shall Live?

So now we have ‘death by numbers’, in this case the number calculated by measuring QALYs. But is this fair? This kind of calculation determines entitlement to an earlier treatment intervention in terms of ability to benefit, and so favours the young man. But both he and the woman could last longer on dialysis, whereas, if the older man is put at the end of the queue, he will certainly die quite soon. Does he deserve this, because he failed to be fully compliant with treatment in the past? Shouldn’t he be given a second chance? And what about the mother with young children? Is it right that she is made to stay longer on dialysis, while the young man who has no dependents gets the most effective treatment? Maybe ability to benefit is not the only criterion we should use when deciding how to ration scarce resources.

An Interlude - Two Exercises

I remarked earlier in the chapter that we will need a really sophisticated account of justice in order to deal with the problems of fair allocation that we are encountering. Now that need seems even greater, but, rather than try to spell out possible theories right away, we can approach the challenge by means of two exercises or roleplay games. I shall describe two scenarios below, which require some sort of criterion for fair allocation. If you are reading this on your own, put yourself in the situation of one of the characters in the scenario and consider what solution you would offer. You can also do this in a group, or introduce it in a classroom situation, asking volunteers to take the various roles. (I have done this many times, with a very wide range of groups in the UK, New Zealand and Singapore.)

Scenario One: The Birthday Cake

You are at a birthday party for a six-year-old. There are five of you and you are all about the same age (either already six or soon to be). A large, round cake is brought in and
someone has to decide what is a fair way to share it out. All five children like the cake and no one is allergic to it. How is the cake to be divided, and why is this fair? (Do not read on until you have decided on a solution and your reason for it.)

Several solutions may be suggested to this problem. The simplest one may be to cut the cake into equal shares, though this can be difficult with a circular shape and five pieces (unusual to have a protractor at a birthday party!). To meet this practical problem various procedural solutions may be suggested. One is to get a parent or other adult to cut the cake, on the assumption that they will do so impartially. Another is the ‘one cuts/the others choose’ procedure. This means that the person cutting will strive to make the slices equal, since the others are likely to choose any larger slices. A second type of solution is role-related. A parent, as the host of the party, can be seen as the one entitled to make the distribution – and well motivated to keep everyone happy!

Another role-related one is to let the birthday girl or boy cut and distribute the cake. This may seem unfair at first, but, since everyone is assumed to be in this role at his or her own party, this privilege is eventually shared equally by all. A third type of solution leaves it to individual choice: each child can say how much they want, and these choices are unlikely to create huge disparities in sharing, since all are likely to want to be seen as fair. Finally, there is the sharing or gratitude type of solution. One of these solutions is to cut the cake into six slices (easier!), and then to offer the parent the extra slice (gratitude); another is for all to take small portions, each roughly equal, and to leave the birthday person to share the rest with their family or with friends who could not be present (sharing).

This may seem like a trivial exercise, but it does illustrate some important principles of justice. The first is the assumption of equality in justice. If no one has any special need for, or any special claim on, the cake, then either equal shares or individual choices seem fair. The cake is a luxury, not a necessity, and so no one is likely to be disadvantaged by either the attempt to cut equally or the reliance on people’s sense of good behaviour in taking a share. The procedural and role-related solutions are also based on equality as a value – equally shared privilege or reliance on impartiality (symbolized by the blindfold on the figure of Justice who holds the scales in the Courts of Justice). But a new dimension comes from solutions which allow for gratitude and sharing with others, since these represent a change in orientation from ‘getting’ to ‘giving’, and suggest that even when luxury is involved, justice can be more than individual entitlement – it can also reflect communal values.

Scenario Two: The Lifeboat

The second scenario is a much more serious and difficult one. (The same role players should be used, but in this case there is a sixth person to consider, as we shall see.) The situation is that a lifeboat is adrift in an isolated part of the ocean with no wind. Its
ship has sunk suddenly and no May-day messages have been sent. The boat has only one set of oars (no other means of propulsion) and there is no prospect of wind or rain. An inspection of the supplies shows that there is only enough food and water to last five people for four days, if shared out equally. However, it is known that the nearest land is 10 days of hard rowing away. The five characters on the boat are a frail old lady, a middle-aged sedentary worker who is somewhat overweight and has a heart condition, a young woman who is breastfeeding a baby (the sixth person) and two physically fit young men, one of whom has a mild intellectual impairment. It is also known that this second young man may have been molesting young children, though this has not been proved.

How are the rations to be shared out so that justice is ensured? (As before, think of your own answer to this problem before reading on.)

The seemingly obvious answer to this dilemma is a utilitarian one, based on the assumption that at least some of the people in the boat should be enabled to reach land and survive (the greatest happiness of the greatest number). Clearly, on this assumption, the young men are essential (and also possibly the middle-aged man). They will need enough sustenance to be able to row the boat for 10 days. The old lady is of no value in this calculation, and is unlikely to survive anyway, so should not be allowed to use up any of the precious supplies. The young woman and her baby present a problem. She will need to avoid dehydration, if she is to keep a supply of milk, so cannot row, and she will need a lot of water. It may be that, to ensure survival of at least some of the people on board, the baby will have to be allowed to die and the mother used as a fourth rower.

Of course, this is a brutal solution to the problem, and many people will shy away from it, looking for an alternative. To do this, people have to question the basic premise that survival (at least of some) must be ensured at all costs. One way of trying to avoid the logic of sacrificing some lives so as to save others is to appeal to a voluntary principle. All, it can be said, have an equal right to the rations, since everyone’s life is of equal worth, but some people may choose to forego their share for the sake of the others. So, for example, the old lady may feel that she has lived a long life and that she should do all she can to help the younger people survive, even at the cost of her own life. The middle-aged man may try his best to row, though fearful that his heart could give out, and so he may die in the attempt. It will be hardest for the young mother. How can she offer to abandon her baby and help the others survive? It seems unlikely that she would do so, without being coerced into it. Thus, little help may come from the voluntary principle. The baby may have to be forcefully sacrificed.

A different solution entirely is to reject totally the assumption that survival (at least of some) is all that matters. Survival with dishonour and an enduring sense of guilt could be worse than death. Therefore, the value of each person’s life is ranked
equally and the group must co-operate to give everyone enough food and water, even at the cost of never reaching land. In this account, justice means responding proportionately to each person’s need, without discrimination against anyone on grounds of utility.

**Principles for Just Health Care**

We can now return to the problem of finding an adequate theory of justice in situations of scarcity of health care. Based on the above scenarios, we can see several possible principles that might be used to decide how to allocate fairly:

1. To each an equal share
2. To each according to individual choice
3. To each according to potential for future life years
4. To each according to what they deserve
5. To each according to their social usefulness
6. To each according to their needs.

We have seen already that in situations of necessity (health or survival on the lifeboat), as opposed to situations of luxury (the birthday cake), equal shares do not seem to be fair, since this will mean some people will have more than they need and some less. The second principle also causes problems, since we cannot guarantee that people will make individual choices that are fair to everyone. (However, there may be another way of enabling individual choice, through an agreement on fair procedures, and I shall return to this later.) The third option, life-years ahead, seems acceptable as an individual choice (the old lady volunteers to starve), but if this is imposed on people it leads to unacceptable ageist discrimination. Groups doing the exercise rarely go for the fourth option (desert or merit), though some may think of it in relation to the suspected child abuser. (In the birthday party the person who has the birthday can be seen as deserving special treatment, but then each person will have the same special day.) The main problem with the notion of desert is that it can be both subjective and inconsistent. For example, we may say that persistent smokers deserve lung cancer, since they could have prevented it, but then how far will this principle extend? Do obese people deserve their diabetes, highly stressed executives their heart attacks? We do not know how far we can hold people individually responsible for their detrimental conditions – and this is certainly true of the ambiguous situation of the young man with intellectual disability. Thus, a desert or merit principle can be seen as posing the danger of being unfair.

This leaves us with two principles: one based on utility and the other on needs or rights. These correspond to two of the ethical theories we discussed in Chapter 2,
utilitarian theory and deontological theory. In the former theory, social benefit is the final arbiter. Ideally all individuals should have the hope of happiness or well-being, but, since (as Jeremy Bentham said) ‘all shall count as one and none as more than one’, the individual will have to be subordinated to the welfare of the majority. When this is applied to health care rationing, some groups would have to be favoured over others, since they have more to contribute to the general welfare, and so the allocation of resources to those who are of little or no use to society would be unjust to the majority. This theory, if followed to its logical conclusion, would have serious consequences for health care provision. For example, it implies that the state should not pay for facilities for the severely intellectually disabled (though parents could be allowed to pay for them out of their own resources), and it would seem to give priority to young, highly qualified persons who can contribute best to the prosperity of the society, at the expense of the elderly and those who are physically or mentally chronically ill. These logical outcomes of utilitarian theory have led people to see it as ‘brutal’ or ‘inhumane’, like the scenario on the lifeboat that sacrifices both the baby and the old woman. On the other hand, as we shall see, those theories that argue for an equal consideration of everyone’s needs can be seen as impossible to implement. Thus, some people may favour some form of moderated utility theory, where some attention would be paid to the needs of the non-productive members of society (in consideration of the unhappiness the majority would feel if they were totally neglected), but priority would clearly be given to those who can create most social benefit.

The alternative, deontologically based theory sees every human being as equally deserving of consideration and respect, and so everyone should have equal access to services that meet their health needs. But how will this work in practice, when there are simply not enough resources to meet everyone’s needs? The UN Declaration of Human Rights (1948) states:

Everyone has the right to a standard of living adequate for the health and well-being of himself and his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.

(United Nations, 1948, Article 25 (1))

We should notice that this is not the ‘complete physical, mental and social well-being’ advocated by the WHO Charter. It is describing a threshold, a basic minimum, below which no one should be allowed to fall. How, then, might this minimum be defined?

Answering this question requires us to look first at general theories of distributional justice, other than the utilitarian one just discussed, and see how this might help us to define a basic minimum health status.
The most influential of such theories has been that of the political philosopher John Rawls. In his monumental work, *A Theory of Justice* (1973), Rawls imagines a hypothetical situation in which people who are free and rational but under a ‘veil of ignorance’ would decide what kind of society they would wish to be members of. The ‘veil of ignorance’ ensures that they know nothing about their own abilities, likes and dislikes, conception of the good, or position in society. Rawls argues that the rational way of ensuring that this society is fair to everyone would be to agree to two fundamental principles of justice. He calls these the Liberty Principle and the Difference Principle. These principles are in ‘lexical order’, which means that if there is conflict between the principles, then the first one must take priority. This approach to justice can be called a ‘social contract’ theory, since it is based on the idea that, given a choice, people would agree to this kind of social arrangement. (We can see that this is one way of using the voluntary approach to gain agreement to a fair procedure, but it is very theoretical, since no one actually makes an agreement of this kind.)

Rawls (1973) defines the fundamental principles of justice as follows:

**First principle**

Each person is to have an equal right to the most extensive total system of equal basic liberties compatible with a similar system of liberty for all.

**Second principle**

Social and economic inequalities are to be arranged so that they are both: (1) to the greatest benefit of the least advantaged ... and (2) attached to offices and positions open to all under conditions of fair equality of opportunity.

(p. 302)

We can see at once that Rawls does not believe that justice requires that everyone have an equal share of social or economic resources. He argues that differences in income and social status are inevitable in a free society (and also perhaps desirable, since they will motivate people to achieve improvements in their status). Justice requires only that people have an equal opportunity to improve their situation, but he does concede that attention should be paid to improving the lot of those most disadvantaged by the social and economic differences. This is known as the ‘maximin’ principle, and it would (Rawls believes) prevent massive exploitation of the poorest members of society merely in order to make the rich richer.

So where does health status come into this theory? Another philosopher, Norman Daniels, has proposed that we can include this in the requirements for equal opportunity. He claims that, since ill-health can severely compromise a person’s ability to pursue their life plans, justice requires that we remove the disadvantages caused by health and disability. This means that people have a right to those health care
interventions that will allow them to pursue the ‘normal opportunity range’ for their society (allowing for differences here according to a person’s age or degree of disability). So a person will be below the threshold for a minimum health status when they are not enabled to make the range of choices that others with an acceptable level of health (but like them in all other relevant respects) are able to make (Daniels, 2008).

Another writer, Lennart Nordenfeldt, has offered a similar criterion, since he also refers to a person’s capacity to pursue his or her chosen goals in life. Nordenfeldt (1987) refers to these as ‘vital goals’ and he defines health as follows:

A is in health if, and only if, A has the ability, given standard circumstances, to realize his vital goals, i.e. the set of goals which are necessary and together sufficient for his minimal happiness.

(p. 97)

A feature of both of these accounts of health is that they do not refer to the absence of disease as the main criterion. In fact, both accounts would allow for us to describe a sick, or even dying person, as healthy if he or she could pursue those goals, which are seen as ‘vital’ to them (Nordenfeldt), or which it would be reasonable for anyone else in these circumstances to be able to pursue (Daniels). So, for example, we might say that a minimal threshold of health care provision for dying patients is that they be provided with adequate terminal care, so that they can be sufficiently free from pain, indignity and distress to say goodbye to those they love. They ought to be enabled to pursue their ‘life plan’ for their dying days.

Such accounts of the nature of health are relatively modest in their criteria for a decent minimum of health care, and so may be of some help in the dilemma about rationing scarce resources. For example, they may help to moderate the tendency to use highly expensive interventions to keep people alive at all costs, even when they are left in a state in which they have no opportunity to pursue any life goals any more, or even to communicate with those they love. But they do leave some unanswered problems. One is the allocation of life-changing interventions (such as organ transplants) when all potential recipients could benefit in terms of approaching more closely to the ‘normal opportunity range’ or having a better chance of realizing their ‘vital goals’. And there is a more profound problem: because these accounts make the definition of health relative to a person’s specific society, or to personal awareness of what will make them happy (a totally subjective definition of health), they are in danger of overlooking gross disparities in health status both within nations and between nations. If a person has learned to live with a very low expectation of what is needed to make them happy, or if people live in societies or groups where the overall health status is very low, are we to say that they have been treated justly? Is there no more objective criterion of what is simply not humanely acceptable as a ‘normal range’ of health? That
question raises the issue of global inequity in health, to which I now turn.

**Global Inequity in Health**

The statistics on health inequalities in the world as a whole paint a grim picture. A child born in Swaziland is nearly 30 times more likely to die before the age of five than a child born in Sweden. (There are 119 deaths per thousand births in Swaziland, compared with 4 in Sweden.) A child in Cambodia is 17 times more likely to die in its first five years than is a child in Canada. Worldwide, one death in three is from communicable disease (examples include AIDS/HIV, tuberculosis, polio, malaria and measles), yet almost all these deaths occur in the low-income countries. The relative infrequency of death due to communicable disease in the industrialized world shows what could be achieved if there were a real commitment to global health equality (UC Atlas of Global Inequality).

In 2008 the WHO published the final report of its Commission on Social Determinants of Health. The report pointed out that:

*Where systematic differences in health are judged to be avoidable by reasonable action they are, quite simply, unfair ... Putting right these inequities – the huge and remediable differences in health between and within countries – is a matter of social justice ... Social injustice is killing people on a grand scale.*

(World Health Organization, 2008, p. 3)

The Commission argued that lack of access to health care is only one small part of the array of social determinants that create this injustice. The other factors are ‘caused by the unequal distribution of power, income, goods, and services, globally and nationally (p. 4)’. As a result of this people not only lack adequate health care, they also have inadequate and insanitary living conditions, minimal or no education, dangerous work environments and insufficient income to support themselves and their families. The report urges action in three areas in all the countries with poor health outcomes (including richer countries with disadvantaged groups):

1 Improve daily living conditions;
2 Tackle the inequitable distribution of power, money and resources;
3 Measure and understand the problem, and assess the impact of possible actions to deal with it.

The importance of this approach to global health inequity is that it broadens the debate from the worries of the richer countries about escalating health care costs to more fundamental questions about the basic social arrangements in a society. Of
course, this is a politically difficult move to make, and the WHO does not have the power to make governments and international commercial and financial institutions change the policies that are causing such massive health problems for the majority of the world's population. In terms of bioethical theory, however, this broader canvas for looking at justice in health seems essential. It is no longer possible to contain the discussion of health priorities within national boundaries, and to recognize this we have to make the move from a 'right to health care' to a 'right to health.' I shall now discuss an alternative theory of health justice which attempts to do this.

The Capability to be Health (CH) Theory

The theories we have looked at so far either are based on majority benefit (utilitarianism) or on some kind of social contract based on a specific society's norms (the 'normal opportunity range' of Daniels or the 'vital goals' account of Nordenfeltd). But an alternative approach to both of these theories is one which sees a universal right to health, based on an understanding of the equal worth and dignity of every human being. This is a theory of moral entitlement, based on the accounts of two contemporary philosophers, Amartya Sen (2009) and Martha Nussbaum, but fully developed in Sridhar Ventatapuram’s book Health Justice (2011). The theory asks the question: What is every human being morally entitled to in terms of their health status? To answer this, it considers the four factors that are the causes of an individual’s health and longevity. These are: biological endowments and needs, individual behaviours, physical environment and social conditions. Injustice in relation to health occurs when people suffer premature death or impairments, which are preventable. The CH theory argues that while the biological endowment probably cannot be significantly changed and the health-destructive or -enhancing behaviours of an individual are that person’s responsibility, the health-destructive effects of both the physical and social environments (the factors identified above by the WHO report) are able to be changed. Thus, there is a social obligation, not to achieve perfect health outcomes (since these will also depend on biological and personal responsibility factors), but to alter those physical and social conditions which destroy health, and to change them into ones which enhance people’s capacity to be healthy. Health injustice occurs when, nationally and internationally, we fail to make those changes that would give people a real chance to lead longer and healthier lives. Although this theory is not in any sense a religious one, its basic premise is perhaps summed up in the ‘Serenity Prayer’ of Alcoholics Anonymous (a prayer originally written by the American theologian Reinhold Niebuhr):

God, grant me the serenity to accept the things I cannot change,
The courage to change the things I can,
And the wisdom to know the difference.

Of course, this prayer relates to individual serenity and resolve, but its message about the courage to change echoes the challenge of this approach. Like the WHO document, it is arguing that failure to tackle those social factors that reduce people’s capability for health is ‘killing people on a grand scale’, and so cannot be seen as morally right.

However, this theory is still at a somewhat general level. What are the specific capabilities that are needed to enhance health and to ensure that there is a universal respect for human dignity? Martha Nussbaum (2006) suggests a list of attainable human capabilities that we should see as normative. They are:

1. Being able to live a normal length of lifespan;
2. Having good health;
3. Maintain bodily integrity;
4. Being able to use senses, imagination and think;
5. Having emotions and emotional attachments;
6. Possess practical reason to form a conception of the good;
7. Have social affiliations that are meaningful and respectful;
8. Express concern for other species;
9. Be able to play;
10. Have control over one’s material and political environment.

(Nussbaum, 2006, p. 76–77)

We can see that, with such a wide-ranging list, we are getting back to the holistic definition of health in the WHO charter. The list does not help us to make rationing decisions because of the lack of specification in its terms. For example, what is ‘good health’? And how do we define a ‘normal lifespan’, when life expectancy, at least in the richer countries, is constantly rising? Some other items in the list may not be attainable by everyone, for example, by those with severe physical impairments. But, like the WHO definition, it can set a horizon for health improvement, reminding us that human life has a whole set of dimensions to it, all of which are components of what we should see as health in the broadest sense. Thus, this third kind of justice theory, the ‘capability approach’, takes us back to VE, where human fulfilment is the ultimate goal. We still may not know to whom to give the kidney. However, we can more easily see how social and political policies threaten human dignity on a global scale. Returning to the earlier exercise, we can realize that there is no adequate answer to the moral dilemma of those on board the lifeboat, but at least we can see that there have to be better lifeboats! Thus, eventually bioethics theory can lead to demands for socio-political change.
Birds on the Wing

Another story may help to clarify the kind of moral approach that the CH theory aspires to. Some years ago I was a speaker at a conference in New Zealand looking at the controversy over cannabis use and health. I was going to use an image of bird flight from the writings of Immanuel Kant. He described the folly of a dove resenting the resistance of the air against its wings, imagining that without this it could fly much faster – but of course, without air resistance the dove could not fly at all! So, said Kant, we need the resistance of facts to make our theories work, for without facts our ideas are useless. I was going to say a similar thing about avoiding a debate about cannabis uninformed by reliable data. But I dropped this idea when, in the speech before mine, a Maori health activist used a quite different image of flight to point out how our society failed to care for those prone to drug abuse. Here is how I described his speech when I wrote about it later in my book Health as Liberation (1995):

He spoke of the migration of flocks of birds and of how, as we see them in their graceful and near miraculous flight, we only half perceive what is going on. He spoke of how the lead birds take turns in meeting the resistance of the air and how the aerodynamic shape they create makes possible the long flight of the whole flock. He spoke of how the young and the old and the frail are sheltered within the wedge shape and of how, if a bird is injured or too tired to continue, stronger birds will accompany it down to a resting place and then help it to rejoin the flock still circling overhead.

(p. 3)

Of course, this is instinctive behaviour by the birds, not some kind of moral choice, and human beings are not birds! But the image suggests that we might hope for a human world where such care, protection and encouragement to venture on become the norm for international co-operation in health.

Global Survival

Still, even if this were to happen at least in part (and health inequities have already been reduced over the past decade), it may all be too late. An even greater threat faces our generation: the global survival of the human species itself. This is where bioethics overlaps with environmental ethics, since there is now a constant stream of evidence that human life on earth will be unsustainable if we continue to use resources as we do at present. There are two major and interrelated aspects to this threat to human survival: global warming and population expansion. So far as the former is concerned,
the WHO report (2008) discussed in the previous section pointed to the risk posed by the increasing urbanization of the world's population:

The current model of urbanization poses significant environmental challenges, particularly climate change – the impact of which is greater in low-income countries and among vulnerable subpopulations. At present, greenhouse gas emissions are determined mainly by consumption patterns in cities of the developed world. Transport and buildings contribute 21 per cent to CO2 emissions, agricultural activity accounts for about one fifth. And yet crop yields depend in large part on prevailing climate conditions. The disruption and depletion of the climate system and the task of reducing global health inequities go hand in hand.

(p. 10)

Thus, the failure to control greenhouse gas emissions in the major industrialized countries has a direct effect on the health and, eventually, the survival of those in the poorest parts of the world. But the second factor will eventually affect the whole of the world population: this is the depletion of the world’s resources overall by current population trends and patterns of consumption. This has been fully documented in a report by the Royal Society of London, People and the Planet (2012). The report points out that ‘on a finite planet there are environmental constraints on human population growth and material and energy consumption. Some limits may already have been reached, and fundamental human needs for food, energy and water are at risk’ (Royal Society of London, 2012, p. 82). So we can see that the most significant of all bioethical issues that we have to confront at the present time is not concerned with the dilemmas of health care or with the confusing range of choices that new medical technologies raise from birth to death. Greater than all these challenges is whether we can safeguard our planet and the life upon it for ourselves and future generations. The Royal Society’s report makes it clear that this can happen only if governments throughout the world take decisive action now. It makes a series of recommendations, of which the following are the most urgent (see pp. 99 and 101 of the report):

- **The most immediate way to reduce the negative impact of human activity on the planet is to reduce material consumption of those who currently consume the most.**

- **It is of the utmost urgency to reduce consumption and emissions that are already causing damage, for example greenhouse gases, deforestation, and land use change amongst others.**

- **Furthermore, unless the goal is a world in which extreme inequality persists, it is necessary to make space for those in poverty, especially the 1.3 billion people living in absolute poverty, to achieve an adequate standard of living.**
• Longer-term, the stabilization of the population is essential to avoid further exceeding planetary limits and increasing poverty. This will mean more effective (but not compulsory) use of contraception in countries with high fertility rates.


This final bioethical issue is not really one for debate or uncertainty, or who could doubt that such global survival is absolutely imperative? Of course, there is debate about the extent of the crisis, even in some cases about the accuracy of predictions about global warming (though this is a view often funded by enterprises with a financial stake in denying it). People will also differ in how best to deal with the ecological crisis, and decisive political action is proving very hard to achieve worldwide. However, the scientific credentials of the Royal Society of London (2012) are beyond doubt, and we need to heed its final warning:

Over the next 30–40 years the confluence of the challenges described in this report provides the opportunity to move towards a sustainable economy and a better world for the majority of humanity, or alternatively the risk of social, economic and environmental failures and catastrophes on a scale never imagined.

(p. 105)