

PREVENTING THE EXISTENCE OF PEOPLE WITH DISABILITIES

I When Life Would be “Worth Not Living”

It is commonly held that there are both cases in which there is a strong moral reason not to cause the existence of a disabled person and cases in which, although it would be permissible to cause a disabled person to exist, it would be better not to. Yet many disabled people are affronted by the idea that it is sometimes better to prevent people like themselves from existing, precisely because these people would be disabled. One of their grounds for concern, which will be my particular focus in this paper, is that claiming that there are reasons to prevent the existence of disabled people may be expressive of a demeaning and hurtful view of the status of existing disabled people, a view that may encourage discriminatory attitudes towards and treatment of the disabled.

I will contend that there can indeed be moral and prudential reasons for preventing the existence of a disabled person. But I will argue that it is less obvious than many people assume what, if anything, the recognition of these reasons expresses about disabled people. And I will contend that, even if the recognition of these reasons does express a perception of disabled people that is potentially hurtful, this effect could be offset by the social expression of a contrary view that I will claim is in fact compatible with and equally valid as the potentially hurtful view.

Whether it may be morally objectionable to cause a disabled person to exist depends, in part, on whether the person’s life would be worth living. If it is ever objectionable to cause a disabled person to exist, the objections are surely strongest when the person’s life would be “worth not living” – that is, would have aspects or features that would be bad for the person and that would decisively outweigh those, if any, that would be good. Such cases are, however, quite rare. Indeed, some people question whether there are *any* disabilities so severe as to cause life to be worth not living. It can be argued that disability involves only the absence of certain abilities and that mere deficits cannot themselves make life too burdensome to be borne. Even if this is true, however, disabilities are often concomitants of *conditions* that not only deprive the victim of certain abilities but also inevitably cause great suffering. If, therefore, we assume that such “disabling conditions” come within the rubric of “disabilities,” it seems clear that some disabilities can be so severe as to make life worth not living. If the bad effects of such a disability would be present at birth, or if they would appear early and euthanasia would not be an option after their appearance, it seems that there can be a strong moral reason not to cause an individual to exist if he would have the disability.¹

The objection to causing such an individual to exist might be wholly impersonal in character. To cause such an individual to exist might be worse, not because it would be worse for that individual, but because (for example) it would increase the net amount of misery in the world. Alternatively, the objection might be that to cause such an individual to exist would be bad for that individual. To exist can be bad for that

individual even though it would not be *worse* for him. For to say that a state of affairs would be worse for an individual implies that there is an alternative that would be better for that individual. But the only alternative to coming into existence is never to exist, and there is no one for whom never to exist is better than existence. So if one refrains from having a child in order to avoid doing what would be bad for that child, there will be no one whom one has prevented from having a bad life. There may never be any actual individual for whom what one has done was better.

Beyond these brief remarks, I will not be concerned in this paper with cases in which a disabled person's life would be worth not living. I will focus instead on cases in which, although the disability would sufficiently severe to make it probable that the disabled person's life would be less good *for the person himself* than an otherwise similar life without the disability, it would nevertheless not be so severe as to make the life worth not living. (It should be explicitly noted that such a claim about a certain type of disability is merely a generalization. At least in the case of most disabilities, and probably in the case of all merely physical disabilities, there is no reason to believe that they *necessarily* make a life go less well than it could have gone without the disability. Some disabled people, indeed, have lives that go conspicuously better than the lives of most people without disabilities. Thus the claim is only that some disabilities make it *likely* that the life will go less well.)

II Disabled-or-Normal Choices

Once we restrict our attention to disabilities that in general allow for a life that is worth living, it becomes important to distinguish between two types of case. In describing these cases, I will focus on the most common way of causing a person to exist – namely, having a child. The first type of case involves a choice between having a disabled child and having a different child who would be “normal” – by which I mean nothing more than “not disabled” or “lacking a disability” – instead. Let us call this a *Disabled-or-Normal Choice*. The second type of case involves a choice between having a disabled child and having no child at all. Call this a *Disabled-or-None Choice*. I will focus primarily on cases of this second type. First, however, I will briefly discuss Disabled-or-Normal Choices. And I will return to these cases again in section VI.

Suppose that a couple discover that one of them has a condition that would cause any child they might conceive now to have a disability that, while allowing for a life that would be worth living, would nevertheless cause substantial suffering and restrict the range of goods accessible to the child. If, however, they delay conception for three months while the condition is treated, they will then be able to conceive a child without a disability. Because this normal child would be the product of the fusion of different gametes, it would be a different individual from the child they would have if they were to conceive now.²

Most people believe that, in these conditions, it would be better if they were to delay conception in order to have the normal child. But the reason why it would be better cannot be that to have a disabled child would be worse, or bad, for the child. For by

hypothesis the disabled child's life would be worth living, and it cannot be bad for an individual simply to be caused to exist with a life worth living.

Some have argued that to cause a person to exist with a certain disability can be wrong because it violates that person's rights, even if the person's life is worth living. I have argued elsewhere that this is implausible – for example, because it implies that it would violate an infant's right, and therefore be wrong, to *save* its life if the only way to save it involved causing it to have this same kind of disability.³ But I will not rehearse that argument here. My concern in this paper is mainly with the expressive significance of certain views and I suspect that most disabled people would be indignant to be told that their lives are such that their simply being caused or allowed to exist was a violation of their rights.

It seems, therefore, that the best explanation of why it would be better to have the normal child is *impersonal* in character. This explanation appeals to a principle advanced by Derek Parfit that I call the *Impersonal Comparative Principle*: “If in either of two possible outcomes the same number of people would ever live, it would be worse if those who live are worse off, or have a lower quality of life, than those who would have lived.”⁴ According to this principle, it is worse if the less good of two possible lives is lived. From an impersonal point of view, it does not matter whether these would be different possible lives of the same person or the possible lives of different possible people.

Two points should be noted about this principle. First, it is limited to the comparative evaluation of outcomes; it says nothing about what one ought to do. It therefore needs to be conjoined with some action-guiding principle – for example, the principle that one ought, if other things are equal, to do what would have the best outcome – in order to support the judgment that one ought, in Disabled-or-Normal Choices, to have a normal rather than a disabled child.

Second, Parfit's formulation of the Impersonal Comparative Principle is explicitly restricted in to *Same Number Choices* – that is, cases in which one's choice will affect which individuals will exist but not the *number* of individuals who ever exist. This principle is therefore silent about any choice of whether or not to cause an individual to exist. Such a choice is what Parfit calls a *Different Number Choice* – that is, a choice that would affect the number of individuals who would ever exist.

The restriction of the Impersonal Comparative Principle to Same Number Choices is problematic because of certain indeterminacies about what counts as a Same Number Choice. Here is one example. Suppose that, as I believe, we do not begin to exist until sometime around the beginning of the third trimester of pregnancy.⁵ In that case, a choice between having an early abortion and continuing the pregnancy may seem to be a Different Number Choice, since it will determine whether an additional person will exist. (A choice of whether to have a late term abortion is what Parfit calls a Same People Choice, as it does not affect either the identity or the number of the people who ever exist.) But suppose a woman in the early stages of pregnancy discovers that her fetus is

damaged in a way that ensures that her child would be disabled. She therefore considers whether to have an abortion *in order to* enable herself to conceive different, normal child instead. Is this a Same Number Choice? Perhaps she may treat it as such and thus be guided by the Impersonal Comparative Principle, despite the fact that, after having the abortion, she may change her mind about conceiving another child, or may be unable to conceive another child. But what if she is considering aborting her defective fetus but is as yet undecided about whether to conceive another child? Here it seems unlikely that the Impersonal Comparative Principle can guide her choice.

This is not a significant problem. But there is a deeper worry about the restriction of the Impersonal Comparative Principle to Same Number Choices, which is that there may actually *be* no Same Number Choices – or, if there are, we cannot identify them. A Same Number Choice is defined by the fact that it does not affect the number of people who *ever* exist. But even a simple choice that causes one person to exist rather than another will almost certainly, given enough time, affect the number of people who will exist. If I cause A to exist rather than B, the number of A's progeny over time will almost certainly be different from the number that B would have had. And A and his progeny will very likely affect other people's procreative behavior differently from the way that B and his progeny would have. So any choice that affects *who* will exist will almost certainly affect how many will exist – that is, it will be a Different Number Choice. Therefore if the Impersonal Comparative Principle is confined to Same Number Choices, its range of application may be restricted to the vanishing point.

Perhaps in applying the Impersonal Comparative Principle we can simply ignore unforeseeable effects on the number of people who ever live. Perhaps, moreover, the considerations underlying the Impersonal Comparative Principle can be applied relatively straightforwardly to certain very simple Different Number Choices, such as the choice between having and not having a child. Suppose, for example, that the reason why it is impersonally better to cause a normal child to exist rather than a disabled child is that the life of the normal child would be likely to contain a greater net amount of good. This suggests that the impersonal explanation of why it is better to cause a well-off person to exist *rather than a less-well-off person* also implies that it is better, if other things are equal, to cause a well-off person to exist *rather than not to cause anyone to exist*.⁶ But if that is right, acceptance of the Impersonal Comparative Principle may commit us to accepting that it is better, other things being equal, to cause more people to exist if their lives would be worth living. And this is a conclusion that most people would resist.

This is one reason for concern about the plausibility of the Impersonal Comparative Principle. Parfit, however, believes that Same Number Choices are sufficiently different from Different Number Choices that the considerations that apply in the former need not apply in the latter. If that is true, we may be able to accept the Impersonal Comparative Principle, applying it to cases in which our choice would not foreseeably affect the number of people who would exist, without being committed to accepting that it would be better to cause more people to exist with lives worth living. But other doubts about the principle remain. It seems, for example, to favor a form of positive eugenics. If, for example, there is a positive correlation between the possession of high cognitive

capacities and having a high capacity for well-being, the principle implies that it is better, other things being equal, to have an exceptionally intelligent child than a child of normal intelligence. If we further assume that there is a reason, other things being equal, to do what would have the best consequences, the implication will be that it is *prima facie* objectionable to have a child of normal intelligence if one could have an exceptionally intelligent child instead.

Although most people object to eugenics, it is not implausible to suppose that there is a moral reason to have a more rather than less intelligent child. But the eugenic implications of the Impersonal Comparative Principle become quite clearly implausible if we eliminate the principle's restriction to the human species. As Parfit states it, the Impersonal Comparative Principle refers to "people." But, particularly because the principle is explicitly impersonal in character, it seems arbitrary to restrict its scope to the human species. After all, if it makes no difference *who* an individual is, it should make no difference what species it belongs to. We should substitute "individuals" for "people" in the statement of the principle. But now suppose that one must choose between having a child and breeding one's horse. It seems that the revised principle must imply that it would be worse to breed one's horse, for the same reason that it would be worse to have a disabled child rather than a normal child: namely, that the horse's life would be less good than that of a human child. Yet it seems that one's reason to have a normal child rather than a disabled child must be different from the reason, if any, to have a child rather than to breed one's horse.

Suppose that, despite these objections, the Impersonal Comparative Principle grounds a plausible objection to having a disabled child rather than a normal child. Does the principle's preference for a normal child rather than a disabled child express a pernicious view of existing disabled people? It is often claimed that to prefer a normal child on the ground that the quality of its life would be higher than that of a disabled child is to devalue the lives of the disabled. It is to imply that the lives of the disabled have less value.

I believe, however, that what is expressed or implied by this kind of preference is benign. We have to acknowledge that some people's lives go better than others'. This is a judgment about the *contents* of people's lives, not about the people themselves. To recognize that a person's life has gone less well than the lives of others is not to disparage that person or to suggest that he matters less or has lower worth or status than others. It is merely to recognize that he has suffered a misfortune, or that he has been less fortunate than others. Similarly, to anticipate that a person's life would be likely to go less well than the lives of others is not to imply that that person would be less worthy of life or that existing people who are relevantly like him matter less or have a lower status than others.

It may be easier to appreciate these points if we focus on cases in which the reason why a person's life would be less good is not that its quality would be lower because of a disability but simply that the life would be shorter. Suppose that one has a choice between having a child with a normal life expectancy and having a different child with a condition that does not cause disability but that inevitably causes death before the age of thirty. The Impersonal Comparative Principle implies, and most of us would agree, that

because a longer life is ordinarily better than a shorter one, it would be better to have a child with a normal life expectancy rather than a different child condemned to die young. This judgment reflects no disparagement of the worth of those who are unfortunate in being doomed to an early death.

III Disabled-or-None Choices

Consider now an instance of a Disabled-or-None Choice. Suppose that some people carry a gene that would cause any child they might have to have a certain disability. This disability would not be so severe as to cause the child's life to be worth not living but would nevertheless be likely to make the life significantly less good than the lives of most people who are similarly situated except that they lack the disability. Many people, if they were to discover that they were carriers of the gene, would seek to avoid having a child, even if they would want to have a child if they could have one without the disability. The expressive effect of this preference may seem pernicious. For this preference is for no child at all rather than one with a disability and may therefore seem to express not just the view that a disabled child is less desirable than a normal child but that a disabled child is positively undesirable, or worse than no child at all. It might be thought to express the judgment that it would be better if disabled people did not exist at all.

It is, perhaps, unlikely that people would find this expressive effect so seriously objectionable that they would conclude that carriers of the gene *ought* to have children exactly as they would if the children could be expected not to have a disability. And even if some people believe that, in deciding whether to have a child, one ought not to be influenced by whether one's child would be disabled, few would conclude that carriers of the gene should or could legitimately be coerced to have children against their will.⁷ But some do hold a closely related view: namely, that social efforts, such as programs that screen for genes associated with disability, that are intended to enable people to avoid having a disabled child ought to be prohibited.⁸ For it can be argued that programs involving screening for disabling genes – especially programs with public financing – grant social recognition or validation to the implied view that the existence of people with disabilities is bad.

I noted earlier my belief that we – that is, individuals such as you and me – do not begin to exist until around the beginning of the third trimester of pregnancy when the fetal brain develops the capacity to support consciousness. If that view is correct, a policy of screening fetuses for genetic abnormalities early in pregnancy, and permitting abortion in the event that an abnormality is discovered, would be a policy that prevents the existence of disabled people and allows different, normal people to be brought into existence instead. It would not be a policy that *kills* disabled individuals and replaces them with normal people. Nevertheless, many people's objections to prenatal genetic testing followed by abortion are inextricably connected to their intuitions about the moral status of fetuses and the morality of abortion. So, if our concern is with the expressive effects of genetic screening, it would be unwise to focus on prenatal screening programs,

since what these programs might be thought to express depends on what those who approve of them believe about the nature and status of the fetus.

In order to separate our beliefs about the expressive significance of policies that prevent the existence of disabled people from our intuitions about abortion, let us focus on programs that screen for genes associated with disability prior to conception. And let us assume that, although some people would seek screening only to enable themselves to be better prepared to care for their child should it be disabled, many would have themselves screened in order to avoid having a child should they turn out to carry a gene that would cause their child to be disabled, or even to have a significant probability of being disabled. And let us assume further that it is entirely predictable that many people will seek preconception screening for this reason and that enabling people to avoid having disabled children is one reason why preconception screening programs exist.

To understand what kind of view preconception screening programs might be thought to express, we must first understand why people would prefer to remain childless than to have a disabled child. The reason cannot plausibly be that to have such a child would be bad for the child. As before, we are confining ourselves to cases in which the child's life can confidently be expected to be worth living. Nor is it plausible to suppose that to have such a child would be bad from an impersonal point of view. The considerations that make it worse impersonally to have a disabled child rather than a normal child do not seem to imply that it would be worse to have a disabled child rather than no child at all. Indeed, as I suggested earlier, it is arguable that these same considerations imply that it would be *better* to have a disabled child than to have no child. If it would be impersonally better, other things being equal, for an additional person to exist with a life worth living, the only difference it would make if the person were disabled might be to reduce the *degree* to which it would be better. (These claims may be false according to impersonal principles that require the maximization of the *average* level of the good. But these principles are notoriously implausible.⁹)

If it is not because of the effect on the child and if having a disabled child would not be worse impersonally, what is the basis of the view that it would be better not to have a disabled child? What would people's reason be for seeking preconception screening? It seems that their concern must be that to have a disabled child would be worse for preexisting people – themselves in particular. The most likely reason, in other words, that possible carriers of a gene associated with disability would have for seeking screening would be to avoid the distress and the burdens of responsibility that would be the likely concomitants of having a disabled child.

This reason for preferring not to have a disabled child does seem to express the judgment that, while a normal child would be welcome, a disabled child would not be worth the burden it would impose. If we socially sanction this judgment by providing preconception screening, that may seem to give emphatic social expression to the view that in general disabled people are not worth the cost, that they are on balance a burden to their parents. And to the extent that screening programs reduce, and are intended to reduce, the social costs of providing care and facilities for the disabled, they might also seem to express the view that the existence of disabled people is a burden to society. A

disabled person might well be prompted to think: “These programs are intended to enable people to avoid having the kind of child that I was, and to prevent the existence of people like me, because they judge that our existence does not repay the effort required for our care.”

It might be tempting to reject these claims by appealing to an analogy with the practice of contraception. Contraception is intended to enable people to avoid having an unwanted child. A policy that legitimizes contraception and makes it available thus caters to people’s almost tautologous evaluation that an unwanted child would be a burden. Yet no one proposes that contraception should be prohibited because it expresses a hurtful view of those who were born unwanted. There is, however, a relevant difference between contraception, which enables people to avoid having a child, and preconception screening, which enables people to avoid having a disabled child. This is that those people who were born unwanted and whose existence might have been prevented by contraception were not unwanted because of any characteristic that distinguishes them from others. The reason they were unwanted would have applied to any other child their parents might have had – that is, to any other person. But disabled people whose existence might have been prevented if a policy of screening had been in effect when they were conceived might have been unwanted precisely because of their disability. And because the disability is likely to be important to their sense of identity, the suggestion that people are unwanted because of *that* can be profoundly wounding.

Can we make the same response in Disabled-or-None Choices that I made in the case of Disabled-or-Normal Choices – namely, that the preference for no child rather than a disabled child implies nothing about the worth of the disabled child and therefore expresses no view of the status of existing disabled people? It does seem true that, in Disabled-or-None Choices, as in Disabled-or-Normal Choices, the desire not to have the disabled child does not imply or express the judgment that the disabled child would have a lower status or be of lesser worth. But the idea that disabled people have lesser worth or status in themselves is not the only hurtful suggestion that might be conveyed by a policy, such as a policy of preconception screening for disability, designed to enable people to avoid having a disabled child. Such a policy may instead express the profoundly wounding suggestion that disabled people are burdensome to others, and that the world would be better without them.

I will argue, however, that we should be cautious about attributing expressive significance either to the preference that a person might have not to have a disabled child or to a policy of preconception screening for disabilities. I will contend that the desire to avoid having a disabled child is essentially perspectival and does not necessarily imply or suggest that those disabled people who actually exist are unwanted or regarded as burdensome.

IV Prospective and Retrospective Evaluations

There is a striking asymmetry between the view that people typically have of the *possibility* of having a disabled child and the view that people typically have of *actually having* a disabled child. Very often, people who would otherwise want to have a child

believe that it would be better for them not to have a child than to have a disabled child. I will call this the *prospective evaluation*. But when people actually have a disabled child, they typically do not regret that they had that particular child. When they discover, at birth or shortly after, that their child will be disabled, they may initially experience a certain rather unfocused regret, but this tends to dissipate rapidly as their love for the child increases. As they become increasingly attached and devoted to their actual child and discover the joys of parenthood, they soon find it impossible to wish that that child had never existed. They come to believe that their lives are actually better with their disabled child than they would have been without a child. I will call this view, which is very common among the parents of disabled children, the *retrospective evaluation*.

In a recent article in the *New York Times*, a woman is reported as saying: “I had a 14-year-old son who died suddenly. ... Knowing he was going to die, would I have said, ‘No, I don’t want him?’ Never.”¹⁰ We might interpret her as saying that if she had known before her child was conceived that he would die at fourteen, she would still have wanted to have the child. If that is her claim, it may involve self-deception based on reading her retrospective view into her hypothetical prospective view. A more plausible interpretation is that if she had known, earlier in her child’s life, that he was fated to die at fourteen, she would still have been glad to have had him and would have believed her life was better for having had him. That is a characteristic and highly plausible retrospective evaluation of life with a child who was the victim of a tragic misfortune.

It might be thought that my characterization of the typical retrospective evaluation omits something important. For while the parents of a disabled child typically believe that it was better for them to have had their actual child than not to have had a child at all, they also believe that it would have been even better for them if they had had their actual child *without the disability*. The question, however, is whether this would have been possible.

There may be cases in which a gene that is responsible for a disability is a necessary condition of a particular individual’s coming into existence. It might be, for example, that if the gene were removed from the gamete that contains it prior to conception, this would lead to the existence of a *different* person. (If, as I believe, we do not begin to exist until later in pregnancy, the removal of the gene from the *embryo* could have the same effect.) This is not to claim that a *disability* is ever essential to a person’s existence. Even if a disabling gene is necessary for a particular person to come into existence, it may be possible for that person to survive the later deletion of the gene, and it is hard to think of a case in which a person could not in principle survive the *cure* of a disability.

Let us, however, put aside the difficult question of whether a particular gene or gene sequence might be necessary for a given individual’s existence. For it remains true that the vast majority of children with a congenital or genetically-based disability *would not* have existed if any of the recognized ways of preventing the disability had been employed prior to the child’s coming into existence. Suppose, for example, that a child’s congenital disability is the result of a preventable or treatable condition of one of the parents. In that case, if the parent had acted to prevent or treat the condition before conceiving a child, this would have affected the timing of the conception and would

therefore have led to the fusing of different gametes, which in turn would have led to the existence of a different child. Or suppose that preconception screening would have detected a genetic defect in one of the parents. In that case, one option for avoiding having a disabled child would have been to avoid having a child altogether. Another might have been to correct the genetic defect. But any of the methods of correcting the defect prior to conception – for example, the removal or replacement of the defective gene in one of the gametes prior to fertilization *in vitro* – would also have led to the joining of different gametes and thus to the existence of a different child.

There is one possible method of correcting a genetic defect prior to the coming into existence of the individual that could, at least in some cases, be employed without affecting the identity of the individual who would exist. If we are distinct from our organisms and do not begin to exist until later in pregnancy, it is possible that genetic therapy performed on an embryo could prevent a disability without affecting the identity of the person who would subsequently develop from the embryo. But in virtually all actual cases, children with disabilities would not, and realistically could not, have come into existence if feasible action had been taken to prevent the disability. When people have a disabled child, therefore, the only realistic alternatives in most cases were for them not to have had a child at all and for them to have had a *different* child without a disability. If the parents of a disabled child realize that the only realistic alternative was for them to have no child at all, their retrospective evaluation is typically that, of those alternatives, it was better for them to have had their actual child. If they realize that it was also possible for them to have had a different, normal child instead, they are typically glad nonetheless to have had their actual child.

It is true, however, that these two instances of retrospective gladness – at having had one's disabled child rather than no child at all and at having had one's disabled child rather than a different, normal child – may reflect different forms of evaluation. I will explain this claim, and explore its significance, in section VI.

Return now to the typical prospective evaluation in Disabled-or-None Choices, the evaluation that prompts some people to seek preconception genetic screening: namely, that it is better to remain childless than to have a disabled child. Given the pervasiveness of the typical retrospective evaluation among the parents of disabled children, people can confidently anticipate, from their prospective point of view, that if they were to have a disabled child, they too would come to believe that their life with a disabled child was better than life without a child would have been. Yet the prospective evaluation remains stable even in the face of the uniformity of the retrospective evaluation among the parents of disabled children. Perhaps we should conclude that the prospective evaluation is simply the product of epistemic limitations and that if people confronted with a Disabled-or-None Choice had a full and vivid sense of what life with a disabled child would be like, they would prefer to have a disabled child, given their initial preference for having a child.

I believe, however, that this is false. The prospective evaluation is not the product solely of epistemic constraints. Consider, for the sake of comparison, the fact that some people who develop AIDS or a fatal form of cancer claim that they are actually glad to

have contracted the disease because it roused them from a form of somnambulism, strengthened their relations with their loved ones, and caused them to value and appreciate their every remaining moment. Most of us, on hearing these claims, acknowledge that these people have experienced a special kind of transformative illumination; yet we continue to prefer not to get the disease ourselves, even if we could be confident that we would gain enlightenment along with it. From our point of view, a fatal disease is too high a cost to pay for the full epiphany. Yet we are reluctant to assert that those who are glad to have become fatally ill are deluded in thinking it has been better for them. Is our evaluation, then, the product of mere epistemic limitation? That seems implausible. We can, at one level at least, understand the illumination when it is explained to us; and many of us, at another level, have had direct glimpses of it. More importantly, if we concede that our preference is just the result of epistemic deficiency, we are conceding that it really would be better for us, if other things were equal, to get the disease if it would also bring us wisdom.

We can, I think, achieve a better understanding of this phenomenon if we consider another example. A friend of mine once told me, when I was considering whether to have a child, that if he had known before he had children how much time they would take from his philosophical work, he would probably have remained childless. But once he had children, he was glad that he had, despite their detrimental effect on his work. Again, it is not that when he had children he achieved a hitherto inaccessible insight into the rewards of parenthood, or that he came to understand that previously he had mistakenly overvalued his work in philosophy. It is, rather, that his values altered or evolved. He simply came to give more weight to the value of personal relations and a lower priority to the values of knowledge and achievement. Similarly, people who are glad, all things considered, to have contracted a fatal illness have come to attribute a higher value to the examined life, and a lower value to quantity of life, than most other people do.

I believe that the transition from the prospective evaluation to the retrospective evaluation is also the result of a shift of values rather than of an overcoming of epistemic limitations. *In general* when people have their first child the priorities among their values tend to alter, often quite rapidly. The child becomes their primary focus of concern and their principal source of gratification. Their work, hobbies and recreations, and even relations with their spouse and friends all begin to matter less. This process occurs in parents of disabled children in much the same way it does in other parents.

In short, I claim that it is a change in values that explains why people who once preferred not to have a child than to have a disabled child nevertheless come to believe, after actually having a disabled child, that their life has been better with the child than it would have been without a child. One objection to this claim appeals to a further evaluation that such people often make. Suppose that both members of a couple are carriers of a defective gene and that consequently any child they might have would be disabled. If they had known this earlier, they would never have had a child. But they discovered it only after the birth of their first child. They now endorse the typical retrospective evaluation: they believe their lives have been better for the presence of their disabled child. But they prefer not to have a second disabled child and believe that it would be worse for them were they to do so. Yet they would welcome a second child if it

would not be disabled. If, however, the explanation of why they now accept the typical retrospective evaluation is that their values have altered in such a way that they now value life with a disabled child, it seems unaccountable that, looking forward, they continue to accept a variant of the typical prospective evaluation – that is, they would like to have a normal child but would prefer not to have another child than to have a second disabled child. This suggests that the explanation of why they are glad to have had their existing disabled child cannot be that their values have changed.¹¹

Even if the pattern of preferences and evaluations described here is quite common, that does not show that the couple's retrospective evaluation does not reflect a shift in values. For there are good reasons why they might believe that a second disabled child would be worse for them that are compatible with their being highly receptive to the goods derivable from being the parent of a disabled child. It might be, for example, that while they are capable of meeting the demands of caring for a single disabled child, the further demands that a second disabled child would impose would take them over a critical threshold to a point at which the burdens of care would overwhelm their resources. Indeed, they might reasonably believe that satisfying the needs of a second disabled child would render them incapable of continuing to provide the level of care that their first child requires. This could be true even if having a second child who would not be disabled would not take them beyond the limits of their capacity to support a family.

There are other possible explanations as well. Although this is less likely, it is possible that, in addition to valuing life with a disabled child, the couple also value variety. Their evaluations might be similar to those of a couple who are in general indifferent between having a male child and having a female child but who, once they had a child, would want to have a second child only if it would be of a different sex from their first.

One might attempt to reinforce the objection by observing that if this couple were in fact to have a second disabled child (for example, through contraceptive failure), they would very likely *again* be glad that they did. If they could honestly express their gladness through the typical retrospective evaluation – that is, if they could sincerely believe that their lives were improved by their having had a second disabled child – that would suggest that my explanation of the shift from the prospective evaluation to the retrospective evaluation is mistaken. For in this case there would be *two* such shifts: one after the birth of the first disabled child and another after the birth of the second. So unless we can distinguish two distinct patterns of values – one that supports the judgment that having one disabled child is better than either remaining childless or having two disabled children and another that grounds the judgment that having a second disabled child is better than having only one – it seems that this couple's evolving series of evaluations cannot be explained by a series of shifts in their values.

This seems right. I therefore think that the best explanation of what happens in most instances of the kind of case I have described is that the couple undergo a change of values (or a change in the priorities among their values) after the birth of their first disabled child and then, after the birth of their second, experience what I will call *adaptation* and *attachment*. These are phenomena that some would claim account for the

typical retrospective evaluation even in the case of a first or only disabled child. I will deny that but contend that they may plausibly explain why a couple who are initially averse to having a second disabled child might later be glad that they did. But before I explain what adaptation and attachment are, I will note another possible explanation of the retrospective evaluation that I think is clearly mistaken.

I have claimed that people who were averse to having a disabled child but have nevertheless become the parents of one are typically glad, in retrospect, to have had the child. Yet their retrospective gladness does not show that their having had the child was in fact better for them. There are various reasons why one might be retrospectively glad that one's life has gone the way it has even though it would have been better for one if it had gone differently. Putting aside explanations having to do with such obvious considerations as false beliefs about what one's life would otherwise have been like, I will discuss two types of case involving retrospective gladness that are relevantly different from the case in which people who initially accepted the typical prospective evaluation are nevertheless glad, in retrospect, to have had a disabled child.

In some cases, retrospective gladness that one's life has gone a certain way is the result of a shift of values that is recognizably a *corruption*. An idealistic person might, for example, take a job in politics and later be glad that he did, but the gladness might reflect the person's having been seduced into enjoying the exercise of power as an end in itself, a condition that would have been alien and repugnant to his former character and values. While he may believe that his life has gone better as a result of his entering politics, this evaluation is made relative to his present values, which are inferior to those he would have had had he not gone into politics. From a more objective perspective, his life has actually gone worse. If the gladness that people feel in having had a particular disabled child were analogous to this – that is, if it were the result of a deterioration of character or values – their retrospective evaluation would clearly have less significance than in fact it has. But I take it to be obvious that the values that lead people to believe that their lives are better with a disabled child than with no child at all are neither corrupt nor in any other way inferior to the values that support the typical prospective evaluation. The values that ground the typical retrospective evaluation are, in the main or perhaps entirely, just the familiar *parental* values that lead people to want to have children or to be glad they have them. (I will say a little more about comparisons among sets of values in section VI.)

A person's retrospective gladness at having had a disabled child rather than remaining childless should also be distinguished from a second kind of retrospective preference, one based on *adaptation*. Looking back on their lives, people often realize that there were ways in which their lives could have gone better. In many cases, this is because a misfortune caused the life to veer away from a more promising course. Consider, for example, cases of acquired (as opposed to congenital) disability. A person may suffer a disabling accident that precludes the fulfillment of her most important ambitions – for example, an athlete who aspires to compete in the Olympics may suffer a disabling injury that forces her to formulate new goals that are achievable in her disabled condition. Eventually she may adapt to her new circumstances so completely that she may no longer regret that the accident occurred. Cases such as this, however, often

involve a *narrowing* or *contraction* of the person's values. Although there is no corruption or lowering of values, the person may have to reduce her aspirations, abandoning the pursuit of certain values and concentrating her efforts on a narrower range of values to which she would otherwise have given a lower priority. Because adaptation to an acquired disability often involves this sort of forced retreat from a broader range of values and activities, people can seldom rationally claim to be glad to have become disabled, though they may adapt well enough to have no significant regrets.

There are, however, cases in which a person can *rationally* be glad that her life has gone the way it has, even when she recognizes that it would have been better for her if it had gone differently. Although these cases can include instances of adaptation to serious misfortune, such as a disabling accident or disease, more often they are simply cases in which one realizes that, although one's life has gone well enough, it could have gone better if some event or choice had been different. In these cases, one forms *attachments* to various *particulars* – most notably, particular persons – that are among the elements of one's actual life. One may therefore rationally prefer one's actual life to an alternative life that would have lacked the particulars to which one has become attached, even if that alternative life would have been better.¹²

Cases of this sort are more common than most of us realize. It is, for example, true of almost every married person that he or she could have had a better or more fulfilling life with a different spouse. For, in any particular case, it is exceedingly improbable that the person an individual married was the most ideally suited partner for that person of all the other people in the world. Many people could, in fact, have made a better marriage with someone with whom marriage was once a genuine possibility – for example, a person they dated in college. It might, for example, be true that my wife would have had a better life if she had married her boyfriend from high school rather than me. Suppose that an omniscient being were to assure my wife that this is in fact true: if she had married her high school boyfriend, she would have had a happier marriage and would have had children who would have given her even greater satisfaction than our children have. She could acknowledge that that would indeed have been a better life for her and yet rationally not regret that she has had her actual life instead. Given the attachments to me and her children that inform her actual life, she may rationally prefer this life even though she can concede that she is worse off than she would have been had she made that different marriage.

There is an interesting question about how this kind of case should be understood. I believe that it is implausible to claim that if the alternative life would actually have been better for my wife, her preference for her actual life cannot be rational. We need, therefore, to explain how her preference can be rational if the alternative life would have been better for her. One possibility is to see the alternative life as better *only* relative to the values that would have informed it, treating attachments themselves as values. For *within* that alternative life my wife would have had different attachments and would certainly have preferred that life to her actual one. On this view *each* life – her actual life with her marriage to me and the alternative possible life with a different marriage – would be better than the other relative to the values and attachments within it. Yet it

seems that the alternative life would have been better in a more robust way than this. If we treat attachments as values, we can claim that the values that she would have had in the alternative life would have been better satisfied than her actual values are within her actual life. In short, the *degree* to which the alternative life would have been better than her actual life relative to the values that would have informed it is *greater* than the degree to which her actual life is better than the alternative life relative to her actual values. That explains the sense in which the alternative life would have been better for her, and leaves it intelligible how she could rationally prefer her actual life. For her actual values, including her attachments, which we may assume are not *lower*, are better satisfied in her actual life.

A different way of understanding this case may be to claim that my wife's basic prudential values – happiness, contentment, satisfaction in marriage, etc. – would have been the same, and would have been better satisfied, in the alternative life. And that is why that life would have been better for her. On this view, attachments do not count as values, perhaps because we seldom have generalizable reasons for being attached to one person rather than another. Unless, therefore, there is some general, objective reason why it is better to be attached to one person rather than another, one's attachments to particular people do not directly support judgments to the effect that one's life is better or worse than some alternative life, though they may support rational preferences for one life over another. On this view, my wife rationally prefers her actual life because of her attachments even though the alternative life would have been better for her even by reference to the values that inform her actual life.

I am uncertain how attachments are best understood. But the important point here is that the typical retrospective evaluation of the parents of a disabled child is relevantly different from my wife's preference for her actual life based on her attachments. For although my wife is glad in retrospect that she made the marriage she did, she is nevertheless obliged to concede that it would have been better for her to have made a different marriage – that is, that there is a robust sense in which her life would have gone better if she had married a different person. But the parents of a disabled child are not obliged to accept that their lives would have been better if they had remained childless. While they may have believed prospectively that they would have had better lives by remaining childless than by having a disabled child, they now believe that their lives have been *better* for having had a disabled child. Their retrospective evaluation is not merely a rational preference for what is in fact the worse of two possible lives.

V Pluralism

I have claimed that people who are as yet childless very often believe that it would be worse for them to have a disabled child than to remain childless. Yet if they in fact have a disabled child, they typically come to believe that it was better for them to have done so. What is curious about these evaluations is that, although they seem to conflict, neither seems mistaken. The people's prospective evaluation seems plausible and, if they had in fact remained childless, they would no doubt have persisted in making that evaluation, even if they had had ample exposure to other people who were glad to have had disabled children. But their retrospective evaluation seems equally plausible. I

suggested earlier that it would be overly simplistic to resolve the apparent conflict by treating the retrospective evaluation alone as correct by virtue of its being made in epistemically superior conditions. It is tempting, therefore, to conclude that *both* evaluations are correct. But is this even coherent?

Because these evaluations do not contain temporal indexicals such as “now,” it seems that the time at which they are made cannot make a difference to their truth or falsity. Thus Derek Parfit notes that “we cannot consistently make a claim and deny this same claim later.”¹³ He contends that, if it *was* true earlier that it *would be* better if a certain individual were not to exist, it must be true *now* that it *would have been* better if this individual had not existed.¹⁴ Applied to the case of the parents of the disabled child, this implies that their prospective and retrospective evaluations cannot both be true.

I believe, however, that the prospective and retrospective evaluations can both be true. They can both be true if a certain kind of pluralism about values is true.

The relevant form of pluralism is now commonly acknowledged. And it is recognized at both the individual and social levels. Most people now accept, for example, that different societies can have different *cultural values* and that, within a certain range, no one set of these values is better or worse than, or superior or inferior to, the others. And this supports the judgment that, again within a certain range, there are diverse ways of life, associated with different cultures, of which none is better or worse than the others. But neither are these different ways of life exactly equally good. If that were true, a slight improvement in one would make it better than all the others. Because each of these different ways of life is neither better nor worse than the others and because it is implausible to suppose that they are all exactly equally good, it is often claimed that they must be incommensurable. And the same claim is often made of the different sets of cultural values that recommend the various different ways of life.

It may seem implausible, however, to suppose that various different ways of life cannot be comparatively evaluated at all. Obviously *some* ways of life can be comparatively evaluated – for example, certain ways of life extolled by Nazi culture are bad and therefore worse than other ways of life. And it is odd to suppose that this commensurability vanishes altogether among ways of life above a certain threshold of acceptability. But is there an alternative? Ruth Chang has argued that it can be true of a set of goods that (1) all are in principle commensurable, (2) none is better or worse than the others, and (3) all are not exactly equally good. She says of such goods that they are “on a par.”¹⁵ I will adopt this suggestion in claiming that different ways of life, inspired by different cultural values, may be on a par. (Nothing of significance hinges on the claim that goods that seem unrankable may be on a par rather than incommensurable. Those who doubt that the relation of parity is a coherent alternative to incommensurability may simply read “incommensurable” where I write “on a par.”)

I believe that a parallel claim can apply to cultural values themselves: one value or set of values may be on a par with another in that neither is superior or inferior to the other and yet the two do not have exactly equivalent status. In some cases, though not in

all, the explanation of why certain *goods* are on a par may be that the corresponding *values* that support or endorse the different goods are themselves on a par.

Just as certain cultural values may be on a par, so may the *personal* values of different people. Personal values are values specific to or embedded in various distinctive individual ways of life. They identify forms of experience and activity that may be good in some lives but not as good, or not good at all (perhaps even bad), in others. But, although personal values are not universal, they may be objective. It is just that whether a particular personal value applies to a given person depends on what that person's individual tastes, dispositions, talents, and so on are. Some people, for example, care enormously about their relations with their family members and friends, while others have a consuming concern for personal achievement. These different values may not be fully combinable in a single life: one may, as Yeats suggested, be "forced to choose perfection of the life, or of the work."¹⁶ Yet these values, and the lives that successfully instantiate them, may be on a par. It is difficult to believe that a life of solitary achievement is, in general, either better or worse than a life of humble devotion and loyalty to those one loves. Yet it is also hard to believe that they could be exactly equally good.

If the different personal values of *different people* may be on a par, so may the different personal values that the *same person* may have at *different times*. The colleague whom I consulted about having children gave priority to the value of achievement at one point in his life but later came to care more about personal relations. This shift in priority among his values seems an instance of neither progress nor decline. For the values that informed his life at different times are on a par.

(There is an interesting question here as to why we resist changes in our values even when we acknowledge that the values that we might acquire, or to which we might give a different priority, are on a par with our existing values. The answer to this question is probably quite complex but one element is presumably that our actual values seem to demand our continued adherence or allegiance even when they do not proclaim their superiority to the rival values. The rival values may seem perfectly acceptable but, because they are *personal* values and are not, at the time, one's *actual* values, they can assert no claim to guide one's action. One's preferences will rationally be dictated by the defensible values that are operative within one's life at the time. Another factor is that changes in one's values can be disruptive of the overall psychological or narrative unity within one's life as a whole. While my colleague was able to accommodate the one change I have described without undue discontinuity, we have only to imagine this kind of change occurring at frequent intervals to appreciate the potential that shifts of value have to reduce a life to a series of fragmentary episodes.)

Thus far I have claimed that different and conflicting cultural values can be on a par and that different personal values, both those of different people and those held at different times within the life of the same person, can also be on a par. It is perhaps worth adding that the different personal values that the same person might have in different alternative possible lives could also be on a par. The idea that different personal values can be on a par enables us to see how the prospective evaluation and the

retrospective evaluation can both be correct. For both these evaluations reflect the personal values of those who make them.

The typical prospective evaluation – made when people do not as yet have a disabled child – is that life with a disabled child would be *worse*. This evaluation, I suggest, is implicitly indexed to the personal values that the people have at the time. Relative to those values, the evaluation may be correct.

The typical retrospective evaluation – made after people have had a disabled child – is that life with a disabled child is *better*. This evaluation is implicitly indexed to the reordered set of personal values the people have come to have as a result of their experience with a disabled child. Relative to those values, the retrospective evaluation may be correct.

The relevant difference between the prospective and retrospective evaluations, in short, is not that they are made at different times but that each is made with implicit reference to a different set of evaluative standards. Of course, if the personal values that inform the retrospective evaluation were inferior to or less defensible than those that inform the prospective evaluation, or if the couple's life with a disabled child were less successful relative to the values that inform it than the life they would have had with no child would have been relative to their earlier values, then it would be highly problematic to claim that the retrospective evaluation is just as defensible as the prospective evaluation. But if both sets of personal values are on a par and the couple's life with a disabled child is no less successful relative to the values that inform it, then there is a clear sense in which both the prospective evaluation and the retrospective evaluation can be correct: each is correct relative to a set of personal values that is on a par with the values to which the other evaluation is implicitly indexed.

Because, moreover, each evaluation is relativized to a different set of values, the two are not in fact contrary to one another. In their role as parents, for example, these people can claim that, relative to the values they have now, their life with a disabled child is better and therefore that the life they might have had without a child would have been worse. But they can and should also accept, as fully compatible with this, that their life with a disabled child is worse, and that the life they might have had without a child would have been better, *relative to* the values they had before they had a child.

(It is perhaps worth noting that we tend to evaluate *other* people's lives in a way that abstracts from the personal values that inform them, which we may not share. We tend to appeal, not to values that are individual or perspectival, but to those that we take to be to the greatest extent universal, including the value of the successful realization of defensible personal values, whatever they may happen to be. Taking up this external evaluative perspective, we might judge that the life a person would have without a disabled child and the life that person would have with a disabled child would be more or less equally good provided, first, that each would be more or less equally successful relative to the personal values that would inform it and, second, that neither set of personal values would be inferior to the other. Or we might judge that the two possible

lives would be on a par. This would be compatible with recognizing that each would be *better* relative to the personal values that would inform it.)

The important point here is that the retrospective evaluation that life with a disabled child is *better* than life with no child is *no less authoritative* than the prospective evaluation that life with a disabled child would be worse. And it is also significant that while the prospective evaluation is of a merely possible life with a hypothetical disabled child, the retrospective evaluation is of life with an actual disabled child. If, therefore, the retrospective evaluation expresses a view about disability, it is that those disabled people *who actually exist* are not burdensome but enrich the lives of their parents and others.

Of course, programs for preconception screening cater to those who accept the prospective evaluation, not the retrospective evaluation. But rather than respond to this by seeking to discourage or prohibit screening for disabilities, perhaps we could seek to offset any expressive effect that screening programs might have by publicly acknowledging or giving social expression to the retrospective evaluation and to the values that support it. How this might be done is a question I will not address, for it is a question of policy, not philosophy. It is enough here to note that any expressive effect that screening programs might have can in principle be countered by giving social expression to the view of disability implicit in the retrospective evaluation, which is no less firmly grounded than the evaluation that prompts people to screen for disabilities.

VI Limitations of the Argument

I will conclude by confessing the limits of my argument. One limit may seem obvious: nothing I have said undermines or eliminates the negative judgment signaled by the prospective evaluation. It might be suggested that my focusing attention on the retrospective evaluation is rather like saying some nice things at the end of a book review to mitigate the harshness of the negative judgments expressed earlier.¹⁷

It is important to see, however, that my claim is not that the prospective evaluation is counterbalanced by the retrospective evaluation in the way that a nasty criticism in a review might be counterbalanced by a bit of praise for a *different* aspect of the book. My claim is rather that the prospective and retrospective evaluations are both valid evaluations *of the same thing*: namely, life with a disabled child. Suppose I tell you that you are ugly. This might be counterbalanced, though not very consolingly, by my adding that you also dress remarkably well. It would be different if I added, perhaps paradoxically, that the claim that you are beautiful is no less true and no less authoritative than the claim that you are ugly.

Still, the core of this objection is sound: nothing in my argument challenges the rationality of the prospective evaluation that life with a disabled child would be worse. But this is unavoidable, for it is in fact rational to believe that life with a disabled child would be worse, even if one recognizes that if one *were* to have a disabled child, one would *then* rationally believe that one's life was better. Given that the prospective evaluation is rational and defensible, it seems that to note that the retrospective evaluation

is no less rational is a better response than to attempt to prohibit screening for disabilities. My argument does not eliminate or impugn the rationality of the prospective evaluation; but neither would a prohibition of screening programs.

I turn now to a second and more disturbing limitation of the foregoing argument. Although I have focused in the previous three sections on Disabled-or-None Choices, the more *common* kind of choice is actually that between having a disabled child and having a different, normal child. In my earlier discussion of these more common Disabled-or-Normal Choices, I considered the *moral* reason for preferring a normal child, claiming that it is impersonal and implies nothing about the moral status of people with disabilities. But I failed to note that the reason for preferring a normal child that is more likely to *motivate* people to screen for disabling genes is not moral but prudential. In general, people prefer to have a normal child rather than a disabled child not because they are concerned with the impersonal value of the outcome but because they believe that a disabled child would be more burdensome to them. Thus to have a disabled child when it would have been possible to have a different, normal child instead is commonly regarded as a misfortune for the parents.¹⁸ It seems, therefore, that people often seek screening in order to avoid the burden of having a disabled child *rather than a normal child*. Thus the expressive objection to screening arises in Disabled-or-Normal Choices as well as in Disabled-or-None Choices. For these choices seem to give social expression to the view that disabled children are more burdensome than normal children and that to have a disabled child rather than a normal child is a misfortune. To accord social recognition to this view may be hurtful to existing disabled people.

Before discussing the expressive objection in the context of Disabled-or-Normal Choices, let me digress briefly to consider a different objection to programs that screen for disabilities, which is that they are *discriminatory*. This charge is sometimes supported by appealing to a comparison with screening intended to facilitate sex-selection. People typically seek screening for disabilities because they believe that having a disabled child would be burdensome in a way that having a normal child would not be. But people in certain societies who want to screen for the sex of the fetus have the same reason: they believe that having a female child would be burdensome without promising many of the rewards they seek, such as perpetuation of the family name, having someone capable of providing for them in their old age, and so on. In societies in which women must take their husband's name and are excluded from remunerative employment, these are not unreasonable concerns. Nevertheless the solution in this case is to eliminate the social discrimination, not to eliminate the victims of it. Sex selection merely affirms and perpetuates the pernicious social discrimination.

Some advocates for disabled people make a parallel claim – that is, that to the extent that a disabled child imposes a burden on the parents, this is a consequence of social discrimination. They contend that disability is relative to the environment, so that if we were to change the environment, what we now regard as disabilities would cease to be disabilities. There is some truth to this; it is true in the case of some disabilities. But it is not wholly true. It is not true in the case of disabilities that involve serious cognitive deficits, nor in the case of disabling conditions that involve suffering or premature death.

And many such disabilities that cannot be wholly neutralized by adjustments to the environment are also correlated with burdens to the parents. So the burdens to the parents of having a disabled child could not be wholly eliminated by eliminating social discrimination in the way that the burdens of having a female child could; therefore screening for disability is not necessarily discriminatory in the way that screening for sex in fact is.

Return now to the expressive objection. The strategy I developed in the discussion of Disabled-or-None Choices cannot, it seems, be extended to Disabled-or-Normal Choices. It is true that, even in Disabled-or-Normal Choices, the parents are very likely to have a retrospective preference for their life with their actual disabled child over the life they might have had with a normal child. But this is unlikely to be relevantly like the parents' retrospective evaluation in a Disabled-or-None Choice. The retrospective evaluation in a Disabled-or-None Choice is typically, as I suggested, that life with a disabled child has been better for the parents relative to the personal values they have developed as parents. But in the case of people who have had a disabled child but could have had a different, normal child instead, it is not true, in general, that their lives have gone better, relative to their personal values, than they would have if they had had a normal child. In fact it is probably true that their lives have gone worse, even relative to their actual personal values, than they would have gone with a normal child. (It is conceivable that life with a disabled child may be better relative to certain slightly deviant or eccentric personal values – for example, those of parents who especially cherish their child's lasting dependency. Whether such personal values could be on a par with more familiar parental values is a question I will not pursue here.)

This is not to deny that, if the parents of a disabled child prefer their actual life to the life they might have had with a normal child, their preference is rational. The rationality of their preference may be grounded in their attachment to their actual child. Their preference is, in other words, analogous to my wife's preference for her actual marriage over a different marriage that would have been better for her. Just as it can be rational for my wife to be glad she made the marriage she did, so the parents of a disabled child can rationally prefer the life they have with their actual child; but they should be willing to concede that the lives they would have had with a different, normal child would likely have been better.

Is there any way to mitigate the hurtful expressive effect of screening in Disabled-or-Normal Choices? We might observe that the claim that a disabled child is more burdensome to care for than a normal child is true only as a broad generalization. In some instances, raising a disabled child is *more rewarding*, relative to almost *any* set of personal values, than raising a normal child. And there are numerous traits that are compatible with normalcy that can make a non-disabled person more difficult to live with or to care for than a disabled person typically is.

More importantly, what seems to be true as a generalization about disabled people is also true, to a greater or lesser degree, of most or even *all* of us individually. Who can honestly claim that he is the best child that his parents could possibly have had, even given their present values? In this respect, disabled people are picked out quite

fortuitously: the characteristics that may cause difficulties for their parents are often associated with genes that can be identified prior to conception. By contrast, there are no prenatal tests for the features of my endowment that have been particularly burdensome to my parents.¹⁹

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NOTES

¹ For a description of a disabling condition – dystrophic epidermolysis bullosa – with effects that cause life to be worth not living and that are present at birth, see Jonathan Glover, “Future People, Disability, and Screening,” in Peter Laslett and James S. Fishkin, eds., *Justice Between Age Groups and Generations* (New Haven: Yale University Press, 1992), pp. 129-30. For a clinical description of the condition, with photographs that give some indication of its grisly nature, see Robin M. Winter et al., *The Malformed Fetus and Stillbirth: A Diagnostic Approach* (Chichester: John Wiley and Sons, 1988), pp. 205-6.

² See Derek Parfit, *Reasons and Persons* (Oxford: Oxford University Press, 1984), chapter 16.

³ See my “Wrongful Life: Paradoxes in the Morality of Causing People to Exist,” in Jules Coleman and Christopher Morris, eds., *Rational Commitment and Social Justice: Essays for Gregory Kavka* (Cambridge: Cambridge University Press, 1998): 208-247. The relevant discussion is on pp. 223-25. A revised and abridged version of this paper is in John Harris, ed., *Bioethics* (Oxford: Oxford University Press, 2001): 445-75.

⁴ Parfit, p. 360. I discuss this principle at length in “Wrongful Life,” section IV of the original version.

⁵ See Jeff McMahan, *The Ethics of Killing: Problems at the Margins of Life* (New York: Oxford University Press, 2001), chapter 1, section 5, and chapter 4, section 1.

⁶ See McMahan, “Wrongful Life,” pp. 234-39 of the original version, and McMahan, *The Ethics of Killing*, chapter 4, section 8.2.

⁷ People do sometimes claim that a good parent should be just as happy to have a disabled child as to have a normal child. I suspect that people think that this claim is somehow implied by the plausible view that it is right and admirable to want, and to try,

to be the kind of person who would love his or her child equally whether it was disabled or not. But in fact it does not follow from this plausible view that it is also admirable to be indifferent about whether one has a normal or a disabled child. It is also admirable to want to be the kind of person who would love his or her child equally even if the child were to become a criminal, but it does not follow from this that it is admirable to be indifferent, in advance, about whether one's child will grow up to be a criminal. (This is not, of course, to suggest that disability is analogous to criminality. The point is only that, if there is no implication in the case of criminality, there should be none in the case of disability either.)

⁸ An important question for those who hold this view is whether it commits them also to opposing social efforts to discourage people from *causing* themselves to have a disabled child rather than a normal child. There are two possibilities: (1) causing a child to be disabled when he or she would otherwise have been normal (for example, through the ingestion of drugs late in pregnancy) and (2) causing the existence of a disabled child rather than a different child who would have been normal (for example, through the ingestion of drugs prior to conception). I am indebted to discussions with Robin Jeshion for encouraging me to address the question of the relation between our views about screening for disability and our views about causing disability, for example through prenatal injury. I discuss this and related questions in another paper provisionally called "Disability: Causing, Countenancing, and Curing."

⁹ See Parfit, pp. _ and McMahan, "Problems of Population Theory," *Ethics* 92 (1981), section _.

¹⁰ "Genes, Embryos, and Ethics," *New York Times*, March 3, 2002.

¹¹ I owe this objection to Tad Brennan, though I have added to his example the stipulation that the couple would like to have a second child if it would not be disabled, so that their ranking of the outcomes is: normal child, no child, disabled child. This addition strengthens the objection because it rules out as explanations of the parents' preference those considerations that often lead people who are glad to have had one normal child not to want a second.

¹² Here I follow Robert M. Adams in his seminal and important paper, "Existence, Self-Interest, and the Problem of Evil," *Nous* 13 (1979): 53-65.

¹³ *Reasons and Persons*, p. 360.

¹⁴ *Ibid.*

¹⁵ Ruth Chang, "The Possibility of Parity," *Ethics* _ (_): _-_-.

¹⁶ "The Choice," in *Selected Poems and Two Plays of William Butler Yeats*, ed. M. L. Rosenthal (New York: Collier, 1966), p. 131.

¹⁷ I owe this objection to Shelly Kagan.

¹⁸ It might be objected that, if life with a normal child is better than life with a disabled child, and life with a disabled child is not worse than life without a child, it follows that life with a normal child is better than life with no child. And that seems a false generalization. In general, being a parent does not seem even presumptively to offer a better life than remaining childless. There are, however, various reasons why the conclusion does not follow. I will note only one. The three comparative evaluations I

have cited seem to be made from a point of view that abstracts from personal values. Understood in this way, the second claim – that life with a disabled child is not worse than life without a child – does not imply either that life with a disabled child is better or that such a life is exactly equally good as life without a child. It must be understood, instead, as asserting that life with a disabled child is on a par with, or perhaps incommensurable with, life without a child. But if A is better than B and B is on a par or incommensurable with C, it cannot be inferred that A is better than C.

¹⁹ I am greatly indebted for comments on an earlier draft to Tad Brennan, David Wasserman, Robert Wachbroit, and audiences at Yale, Ohio State University, and the University of Pennsylvania School of Law.