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Deciding What Is Best for the Child: The Ethics of Different-Child Choices in Reproductive Selection

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Deciding What Is Best for the Child:
The Ethics of Different-Child Choices in Reproductive Selection

A dissertation submitted in partial satisfaction of the
requirements for the degree Doctor of Philosophy
in Philosophy

by

Diane Varley Kierce

2013

ABSTRACT OF THE DISSERTATION

Deciding What Is Best for the Child:
The Ethics of Different-Child Choices in Reproductive Selection

by

Diane Varley Kierce

Doctor of Philosophy in Philosophy

University of California, Los Angeles, 2013

Professor Barbara Herman, Chair

Recent advances in assisted reproductive technologies as well as in preconception, preimplantation, and prenatal screening and testing give prospective parents more information and more reproductive options than previous generations had. But, for families with a history of a serious, heritable medical condition, having more options does not necessarily make it easier for prospective parents to know how to do what is best for their children. Testing is available for a number of conditions for which there is no treatment, leaving prospective parents in a position to make a so-called "different-child choice." If they want to have biological children of their own, they can choose to create only a child that will not inherit the condition or to leave it up to chance whether the condition will be passed on to the next generation. In this dissertation, I consider the moral difficulties that prospective parents in this situation face. I analyze several prominent approaches to selection in different-child choices, including the expressive effects approach made by disability rights advocates, the parental beneficence approach, the parental acceptance approach, and the non-identity problem approach. These existing approaches reach starkly divergent conclusions about the permissibility of reproductive selection in different-child choices. I argue that each of these existing approaches fails to capture the full moral complexity of the decisions these prospective parents face. I then offer my own account of the ethics of reproductive selection in different-child choices, arguing that prospective parents should focus on what is best for the child in their deliberations by acting as a proxy decision maker tasked with evaluating the balance of benefits and burdens for a child born into each possible initial situation. Only by carefully evaluating the expected effects of having a particular condition in a particular family's context can the prospective parents make a good decision in a different-child choice situation. The ethics of different-child choices in reproductive selection are deeply context-dependent, and prospective parents should not expect any easy answers in many of these cases.

The dissertation of Diane Varley Kierce is approved.

John P. Carriero
Christina Palmer
Barbara Herman, Committee Chair

University of California, Los Angeles
2013

For all those who have made, are in the process of making,

or will make a different-child choice

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Gehrman, Ingrid Steinberg, Jesse Summers, and Steve White all discussed my work with me at length as I developed my project, and I am grateful to them for sharing their thoughts, suggestions, and their own work with me.

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VITA

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PART I: INTRODUCTION TO THE PROBLEM

Chapter 1

The Different-Child Choice and Moral Concerns About Reproductive Selection

New parents tend to want their children to be born healthy. Some prospective parents know that they are at a high risk of passing along a serious genetic condition to their children because of their family's medical history. While some of these prospective parents might have morally worrisome motives about controlling what their children are like or trying to create a race of super children, most prospective parents in this situation are presumably motivated by more acceptable or, perhaps, even admirable goals. They want to do what is best for their children. But, what does that look like for prospective parents in this situation? What is it for prospective parents to do what is best for their children when it comes to avoiding a serious, heritable medical condition?

Recent advances in assisted reproductive technologies (ARTs) and various preconception, preimplantation, and prenatal screening and testing options give prospective parents in this situation more information about inheritance patterns as well as more reproductive options than their predecessors from previous generations had. But, having more information and more options does not necessarily make it easier for prospective parents in this situation to know how to do what is best for their children. In what follows I aim to analyze the moral difficulties that prospective parents in this situation face. I will analyze four prominent approaches to this topic and argue that, while they illuminate important features of the ethics of reproductive selection, they each fail to capture the full moral complexity of the choices many of these prospective parents face. I will then offer my own account of the moral complexity of reproductive selection when there is a known risk of passing along a serious genetic condition and there are technologies available to allow prospective parents to select against offspring with the relevant genetic traits.

1.1 The Different-Child Choice

In her book *Carrier: Untangling the Danger in My DNA*,[1] Bonnie Rough describes the decision-making process she and her husband underwent before they became parents. Rough was born into a family with a history of a genetic medical condition on her mother's side of the family, and she struggled with ethical questions about whether she ought to take measures to prevent passing that condition on to her children. In her case, the medical condition that runs in her family is hypohidrotic ectodermal dysplasia (HED). HED is characterized by the inability to sweat as well as having thin, brittle hair and small, round teeth. Unable to cool down the body effectively by sweating, sufferers of HED are vulnerable to heat. The type of HED that runs in Rough's family is transmitted as an X-linked recessive condition, which means that males who have an X chromosome with the HED mutation will have HED. (Females with the relevant mutation in both of their X chromosomes would also have HED, but that would require inheritance of the mutation from both the mother and father. For this reason HED is much less common in females than in males.) Females with one X chromosome with the mutation are carriers and run a 50% risk of passing along HED to

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[1] Bonnie J. Rough, *Carrier: Untangling the Danger in My DNA* (Berkeley: Counterpoint, 2010).

their male offspring. These female carriers tend to have some of the traits characteristic of HED in a mild form—thin hair and small teeth, for instance—but they do not suffer the worst effects of HED. In Rough's case, her maternal grandfather had HED, and her brother has it as well. Thus, without requiring any genetic testing, Rough's mother knew that she was a carrier. As a carrier, her daughters—Bonnie Rough and her sister—had a 50% of having inherited the mutation and, thus, carrier status. As Rough describes in her book, genetic testing revealed that she is, in fact, a carrier and, thus, runs a risk of passing on the mutation to her offspring.

In previous generations, including Rough's mother's, the reproductive options available to those in families like Rough's were few. If a person with a family history of some serious medical condition wanted to avoid passing that condition on to her children she could try to avoid having children at all by whatever methods were available to her, if any, or she could hope for the best, as the expression goes. Increasingly, however, preconception genetic testing, assisted reproductive technologies, and prenatal screening and testing give prospective parents more options. Not all heritable conditions can be tested for, to be sure. But for many conditions, including HED, there are tests available. So, for carriers like Bonnie Rough and others who in the past might have only been able to try to avoid having children or to hope that their children would not be affected, there are now other options for trying to avoid passing on those conditions to one's children.

What options do prospective parents like Bonnie and her husband Dan have? They could use a gamete donor—for either the ova or sperm, depending on which prospective parent has the genetic mutation at issue—who does not carry the genetic risk. There are also sperm sorting techniques that can be used to separate sperm with an X-chromosome from sperm with a Y-chromosome. While it is not 100% effective, this process could greatly increase the odds of preventing a sex-linked condition from being passed along from the father's side. Alternately, the prospective parents could undergo in vitro fertilization (IVF) and have the embryos tested via pre-implantation genetic diagnosis (PGD). Those test results would allow the prospective parents to select for implantation only those embryos that do not have the relevant genetic traits. Finally, they could test prenatally using a technique such as chorionic villus sampling (CVS) or amniocentesis to determine whether the fetus has the genetic trait and use those test results to decide whether to continue or terminate that pregnancy.

All of these options require selecting whether or not a particular zygote will be conceived, implanted, or gestated to term. If elected, these options require selecting a different gamete, embryo, or fetus than one that would grow into an affected child. These options do not provide the ability to prevent passing along a genetic condition to whichever offspring might be conceived. In other words, there is no option (yet) that would allow the parents to alter the genotype or gene expression of a particular gamete, embryo, or fetus, thereby preventing that particular offspring from developing the relevant condition. Rather, the available options provide the ability to select only those offspring that, by chance, do not have the relevant genetic trait to be born. The choice these prospective parents face is a selective choice: this one or that one.

I call the type of reproductive decision Rough and her husband had to make a "different-child choice"[2] choice. It is a *different*-child choice because the technological

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[2] I adopt this terminology from Jeff McMahan, "Causing Disabled People to Exist and Causing People to Be Disabled," *Ethics* 116.1 (2005), 80–81. McMahan defines a different-child choice as "a choice that determines whether one individual or another will exist" (81). Prospective parents may also face a "same-

means currently available offer the option of selecting certain gametes or embryos or fetuses instead of other, different ones in order to avoid passing on the targeted genetic traits. We cannot (yet) offer prospective parents an option of genetic therapy that would change the genetic code or the expression of the relevant genes on the same gamete, embryo, fetus, or child. But, for certain conditions for which reliable screening or effective testing is available, it is possible for prospective parents with a known risk of passing along one of those conditions to avoid creating affected offspring in favor of creating different, non-affected offspring.

Although the choice these prospective parents face is called a different-*child* choice, notice that the choice is not between existing, full-fledged children but between different gametes, embryos, or fetuses. While decisions about which sperm to allow to fertilize which eggs might be morally controversial, the moral concerns raised by gamete donation or sperm sorting are very different from the moral problems with selecting which of two existing children will continue to live when only on can live, as in *Sophie's Choice*.[3] Ethical concerns about choosing to implant some and destroy other embryos

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child choice" (ibid., 79) or a "child-or-no-child choice" (ibid., 80) in which a decision determines whether an existing child (or embryo or fetus) will continue to exist or whether certain prospective parents will create a child at all, respectively. For example, the decision about whether to continue a particular pregnancy when prenatal testing reveals a genetic defect is a same-child choice about whether *this* fetus should continue to develop and be born. Or, if a couple learns through preconception genetic testing that they are both carriers for certain condition or that one of them will develop Huntington's Disease (which is transmitted in an autosomal dominant pattern), they might make a child-or-no-child choice about whether to procreate at all. A decision about whether to implant or destroy a solitary embryo that results from a round of IVF but has a genetic defect is both a same-child choice about what to do with that particular embryo and a child-or-no-child choice if there is no future possibility of creating a different child instead. While same-child and child-or-no-child choices generate challenging ethical questions, many of which overlap with those raised by different-child choices, in this project I consider only the ethics of different-child choices. I refer readers who are interested in these other kinds of choices to McMahan's "Causing Disabled People to Exist and Causing People to Be Disabled."

[3] William Styron, *Sophie's Choice* (New York: Modern Library, 1998).

created in vitro are also different from those involving gamete selection or selecting between two existing children, and all of these, in turn, differ from the ethical concerns about abortion in general and selective termination on the basis of screening or test results in particular. These are controversial matters, and I will not attempt to settle them all here. Yet, my conclusions about the permissibility and impermissibility of reproductive selection in various types of cases depend upon the assumption that the relevant methods of selection are not themselves inherently impermissible. If selection can only be accomplished by impermissible means, it is itself impermissible. My arguments are only meant to apply to means of selection that are not themselves impermissible, but I leave the question of the permissibility of specific methods in their own right for another occasion.[4]

In her memoir, Rough describes her own personal struggle with the question of how having HED affected her grandfather's prospects and well-being. She also wonders if by choosing to use reproductive technologies and/or prenatal testing and selective abortion to avoid having a child with that condition she would offend those who have the condition, including her brother whom she loves dearly. She raises important questions about how the development of new tests and reproductive technologies have changed and

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[4] I suspect that the permissibility of these methods depends upon the moral status of the gametes, embryos, and fetuses at issue and that, while embryos and fetuses have some moral status, they do not have the same, full moral status that existing children have. I believe that gametes, in turn, have less moral status than embryos or fetuses. Thus, I believe that selection of gametes raises little or no question about permissibility, but selective termination of fetuses requires weightier justification because of the fetus's greater (though still not full) moral status. But, I do not argue for that view here. For more on the debate about whether and how it could be that embryos and fetuses could have moral status but not full moral status, see, for example, Warren Quinn, "Abortion: Identity and Loss," *Philosophy and Public Affairs* 13.1 (1984), 24–54; Ronald Dworkin's chapter entitled "What is Sacred?" in *Life's Dominion: An Argument About Abortion, Euthanasia, and Individual Freedom* (New York: Vintage Books, 1994), 68–101; and David DeGrazia, "Moral Status As a Matter of Degree?," *The Southern Journal of Philosophy* 46.2 (2008), 181–198.

continue to change the decision-making process about having children for people in situations like hers. Rough's is a personal account; she does not intend to speak for or make decisions for anyone other than herself. Her account is descriptive, and it tells the story of how she grappled with her own family history and her own difficult decision-making process. She tells her story of the process of trying to figure out, along with her husband, how to make good decisions about having children. Her account is not intended to provide a prescriptive account of the ethics of reproductive choices.

While Rough's book does not aim to provide a prescriptive account of the ethics of reproductive choices in situations relevantly similar to hers, it does raise many of the questions that a prescriptive account ought to answer. In what follows, I aim to answer those questions. Bonnie Rough and her husband faced ethical challenges when they decided to have children, and recent developments in assisted reproductive technologies and prenatal testing both gave them more options and complicated the ethics of making good choices about reproduction. They are not alone in having to make difficult moral decisions about reproduction. Prenatal screening and testing has become increasingly widespread and, in some cases, mandated by law. As a result, prospective parents increasingly find themselves having to make a different-child choice.

1.2 The Moral Concerns Raised by Different-child Choices

For prospective parents who aim to do what is best for their potential future children, different-child choices raise a range of moral concerns. First, there are questions about whether this is a choice they should be making at all. Should parents try to exert increased control over which children they have, beyond selecting their mate and, perhaps, the timing and number of children they create? In the extreme, attempts at controlling—or designing—what sorts of children prospective parents do and do not conceive exemplify the moral failing of not accepting one's children for who they are. That is not what good parenting looks like. Good parents love and accept their children, whomever they are and whatever traits they have. This form of unconditional love and acceptance of family is what makes family relations different from membership in some sort of exclusive club.[5] Perhaps prospective parents are already failing to be good parents in their first actions in that role if they select. Perhaps it makes prospective parents bad people or bad parents if they only want to be parents to certain types of children. Selection might be understood as rejecting certain types of children. If being a good parent requires being accepting of whatever traits your children turn out to have, then selection seems to be exactly the kind of controlling, non-accepting approach to parenting that the obligation to love your children unconditionally forbids.

More broadly, should *anyone* try to control who will come into existence? Reproductive selection bears enough of a resemblance to the morally abhorrent eugenics projects that took place in the twentieth century and numerous fictional dystopian books and films like *Brave New World*[6] and *Gattaca*[7] that a thorough ethical analysis must address concerns about the possibility it crosses a moral boundary, especially since use of

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[5] Leo Kittay gives an argument for why treating a family like a club, with membership restrictions, is morally problematic in Eva Feder Kittay with Leo Kittay, "On the Expressivity and Ethics of Selective Abortion for Disability: Conversations with My Son," in *Prenatal Testing and Disability Rights*, ed. Erik Parens and Adrienne Asch, (Washington, D.C.: Georgetown University Press, 2000), 169–170.

[6] Aldous Huxley, *Brave New World* (New York: Harper Perennial Modern Classics, 2006).

[7] *Gattaca*, directed by Andrew Niccol (1997; Culver City, CA: Columbia TriStar Home Video, 1998), DVD.

preconception and prenatal screening and testing increasingly puts prospective parents into a situation in which they *must* make a selection; they must exert some control over which children come into existence and which do not even if their choice is to refuse to select and leave matters to chance. If it is the case that these are not choices that prospective parents—or anyone—should be making, then we need to reevaluate our biomedical research agendas and take steps to avoid putting prospective parents in a situation where they must make choices that they cannot make well. Even if it is the case that these choices do not amount to some forbidden form of playing God or some other inherently objectionable activity, we benefit from knowing why they do not. That knowledge and understanding informs our understanding of what it is to select in a morally permissible way and how that can and cannot contribute to the parental goal of doing what is best for children.

Another type of moral concern that selection raises deals with the expressive content or the attitudes expressed or endorsed by the decision to select. Does selecting against a particular condition express a judgment about the worth or value of existing people who have that condition? Recall that Bonnie Rough worried that a decision to select against HED would convey to her brother that she thought he should never have been born or that his life was not worth living since he has the condition and she was taking explicit measures to prevent bringing a child with that condition into existence.[8] Harriet McBryde Johnson and other disability rights advocates do, in fact, find selection offensive and take those who select and who advocate selection to be expressing just such derogatory views about people with disabilities. Even setting aside cases in which

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[8] Rough, *Carrier: Untangling the Danger in My DNA*, 12–13.

prospective parents do aim to use selective means to promote these objectionable attitudes, there is a genuine question here about whether selection *necessarily* promotes or is complicit with them. For prospective parents who aim to do well for their children and who reject these objectionable attitudes toward people with disabilities, it is not immediately obvious that it is possible for them to select one way or another without expressing offensive attitudes toward someone.

Another, and, I believe, the most important, moral concern that selection raises deals not with worries about whether an agent has the authority to make such a decision that will affect which children will come into existence nor with the attitude it expresses about existing third parties who have similar disabilities or conditions. This concern deals with the question I began this chapter with, namely the question of how to understand the notion of doing what is best for one's children in the context of a different-child choice. Given the goal of doing what is best for one's children and the limitation of only being able to prevent passing on a trait by selecting to create only certain children and not others, there are difficult questions about the value of existence as opposed to nonexistence and the effects of having a given trait on a child's chances of living a rich, fulfilling life. How should we understand what is better or worse for a child whose values and preferences we do not and cannot know yet because those values, preferences, and even the child herself do not yet exist?

As an introduction to the kinds of moral concerns selection raises, the above descriptions of the main categories of worries are meant to highlight why it is important to think carefully about the morality of selection. Selective reproductive choices bear similarities to various types of moral offenses, and if our society's current approach to reproductive medicine puts an increasing proportion of prospective parents into a situation in which they must select one way or another then we ought to ensure that such selection is morally permissible before we continue with that current approach.

1.3 Existing Approaches to the Ethics of Different-child Choices and Reproductive Selection

Four prominent approaches to the ethical questions surrounding reproductive selection give very different answers about the permissibility of exercising selective options in different-child choices. Very briefly, first, according to bioethicists including John Harris, Julian Savulescu, and Guy Kahane, selection is not only permissible but in many cases morally required. Second, according to Michael Sandel, selection and the desire to select result from an objectionable disposition toward controlling children rather than demonstrating the disposition of acceptance that good parenting requires. For Sandel, then, selection is morally wrong. Similarly, for many disability rights advocates, selection is morally wrong because it expresses offensive, discriminatory attitudes toward people with disabilities. Finally, for those who worry about the non-identity problem and what we owe to future generations, it is difficult, if not impossible, to see how selection could have any moral relevance one way or another given that our choices now can affect which individuals will come into existence in those future generations. So, if prospective parents look to these prominent approaches for guidance on how to do what is best for their children in the context of a different-child choice, they will hear that selection is either required, forbidden, or morally neutral.

I believe that each of these approaches has important considerations to add to the debate. But, given the dramatic conflict among them, they must not yet tell the whole story of how prospective parents like Bonnie Rough, her husband, and others making a different-child choice should think about how to achieve their goal of doing what is best for their future potential children. In what follows, I will argue that by focusing on that goal we can take what is true in each of these four very different accounts, put those kernels of truth into perspective, and identify crucial moral considerations that have not yet been given their due in the debate about the morality of reproductive selection. I aim to develop an account of the ethics of selection in different-child choices that captures the complexity of the relevant considerations and provides guidance to parents making these choices, even as it cannot manage to make those choices easy.

PART II: EXISTING APPROACHES TO THE ETHICS OF REPRODUCTIVE SELECTION

Chapter 2

The Expressive Effects Worry

2.1 The Expressive Effects Worry about Reproductive Selection

Developing, allowing, or even promoting screening, testing, and selection against specific disabilities or medical conditions raises moral concerns about the message those activities send about the worth and value of people with those conditions. Selection against specific conditions seems to express the attitude that people who have those conditions are inferior or undesirable. It seems to express the view that it would be better, in some sense, if people with those conditions were never born. It is, after all, the attempt to prevent just the births of children with those conditions for the very reason that they would have them. Call this the “expressive effects problem” with selection. The fact that researchers, clinicians, and prospective parents would go to great lengths to find ways to select against these conditions seems to entail the view that it would be better for people affected by these conditions never to have been born. And, expressing that view by endorsing or participating in selection can be offensive and harmful to people with disabilities and the kinds of conditions that selection aims to avoid passing on to future generations.[9]

In the last chapter, I noted that Bonnie Rough struggled with the question of what message her decision to select against HED sent to existing people with the condition, especially her brother. She worried that if she decided to terminate a pregnancy in order to avoid passing on HED her affected brother would interpret her actions as expressing the judgment that he never should have been born, that his life was not worth living, or that he was inferior to people who do not have HED. As someone who loves and values her brother, views him as a moral equal, and is glad he is alive and part of her life, she was horrified by the possibility of offending him. She did not want to insult her brother, and she took very seriously the question of what her decision to select would and would not express about her attitudes toward him and toward anyone with HED.

In Rough's case, her worry about insulting her brother turned out to be unfounded because her brother knew her well enough to know that she was not motivated by any such derogatory or offensive attitudes.[10] But, the concern is a real one. Many in the disability rights community object to selection and policies that allow or promote it on the basis of the expressive effects problem.[11] These advocates of disability rights argue that the expressive effects of selection harm existing disabled people, and the attitudes these choices express are derogatory and offensive. Selecting to avoid or terminate

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[9] As John Carriero pointed out to me, the expressive effects worry applies equally to selection in a different-child choice and to decisions not to procreate at all in an effort to avoid creating children with the relevant trait, since if the former sends a derogatory message the latter seems to as well.

[10] Rough, *Carrier: Untangling the Danger in My DNA*, 12–13.

[11] See Erik Parens and Adrienne Asch, "The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations," *The Hastings Center Report* 29.5 (1999), S1–S22, for an overview of the problem and further references.

pregnancies with the aim of preventing the existence of disabilities expresses the view that people with those disabilities are inferior, less valuable, and not deserving of equal respect, according to this line of thought. Further, selection seems to express the view that existing people with at least certain kinds of disabilities should have been aborted because of those disabilities, and it was only because of an inability to detect their condition in time that they were not.

Those who worry about the expressive effects of selection also argue that it sends the message that having a disability—or having a severe enough disability, perhaps—makes it impossible to flourish, i.e., to live a rich and fulfilling life. Being disabled must be viewed as incompatible with flourishing by those who would select. Why else would prospective parents choose not to have an otherwise wanted baby? Yet many people with disabilities can and do live rich, fulfilling lives, of course. Johnson, for one, poignantly rejects the notion that having a disability makes it impossible to live a rich, fulfilling life pointing to her own life as evidence. She describes the physical joy she feels zipping along in her motorized wheel chair and her many professional successes as a disability rights lawyer.[12] In the same vein, Jonathan Glover quotes a woman who wrote into *The Guardian* newspaper in response to a proposal to extend time limits on abortion to allow for prospective parents to make decisions about whether to continue or terminate a pregnancy on the basis of prenatal testing for conditions such as spina bifida, which the quoted woman herself has. The woman catalogs her educational, professional, and personal accomplishments, defending her value and her equal right to be a part of society

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[12] Harriet McBryde Johnson, "Unspeakable Conversations," *New York Times Magazine*, February 16, 2003, http://www.nytimes.com/2003/02/16/magazine/unspeakable-conversations.html.

along with “all its members no matter what race or disability.”[13]

Policies and practices that involve selection have lead Johnson, the woman with spina bifida, and many others with disabilities to feel the need to prove that their lives have worth and that they are just as capable of flourishing as anyone else. For existing people who have the conditions that selection aims to avoid, the practice of selection seems to send a message that their lives are not as worthwhile or valuable as the lives of those without those conditions, putting them in the hurtful, uncomfortable, and insulting position of feeling as though others judge them as inferior or less able to flourish, absent an explicit argument to the contrary along the lines of the defense Johnson and the woman with spina bifida gave of the value of their own lives. But these two examples along with many others do demonstrate that having a disability, even certain moderate to severe disabilities, does not in and of itself preclude a person from flourishing, just as the absence of any disability does not guarantee that a person will flourish. Thus, presence or absence of disability and the ability to flourish are independent variables.

2.2 Reply to The Expressive Effects Worry

If it is the case that practicing, promoting, or allowing selection amounts to an endorsement of the view that having a disability is incompatible with having a rich, flourishing life or the view that people with disabilities are less valuable than others or somehow not deserving of equal moral consideration, then it is offensive and derogatory. But, I argue, selection is not necessarily inherently offensive and derogatory. It is

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[13] Jonathan Glover, “Future People, Disability, and Screening” in *Bioethics*, ed. John Harris (Oxford: Oxford University Press, 2001), 432, quoting an unspecified edition of *The Guardian* from 1987.

possible for prospective parents to choose to select, not out of bigotry, but out of concern for their future child's well-being, and I think that Bonnie Rough's case illustrates this possibility. As I understand her, she respects her brother and others who have HED, understands that they are her moral equals, agrees that they are just as capable of leading rich, fulfilling lives as others, and yet she decides that she wants to bear a child but does not want to bear a child who would be affected with HED. I think she and many other loving, non-bigoted prospective parents can consistently believe that people with serious medical conditions and disabilities are moral equals with people without those conditions and that it is morally permissible for them to select against those conditions in their own reproduction. Thus, if selection and its associated policies are derogatory and offensive, it is because the people practicing or endorsing them in fact do have derogatory and offensive motives not because selection is necessarily derogatory and offensive to existing people with the relevant traits.

Thus, the expressive effects worry, in this, its most basic, form, is best understood as a warning that selection might be used or promoted by those with derogatory or offensive motives and attitudes as a method to harm existing people with disabilities and serious medical conditions. As Glover notes, for many disabled people the hardest or worst part of being disabled is the disadvantage they face because of other people's attitudes toward disability.[14] While many symptoms and physical limitations can be managed or accommodated, other people's attitudes toward disability and people with disability can prove less tractable. Thus, the expressive effects worry shows that sensitivity and care are called for when considering selection and the message it

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[14] Glover, "Future People, Disability, and Screening," 438.

communicates to those who have the relevant conditions. As many disability rights advocates and theorists note,[15] disability is in some ways a social problem, and policies and attitudes toward disabilities ought to minimize those social compounding factors rather than exacerbate them.[16]

2.3 A Further Concern Related to the Expressive Effects Worry: Johnson's Argument that People are Not Fungible

The expressive effects worry can be developed beyond its initial form, however, to raise other important moral concerns. The first is suggested by Johnson's argument against the notion that the presence or absence of a disability is predictive of two potential siblings' comparable "quality of life."[17] Johnson argues that judgments about which of two potential siblings has a better chance of flourishing cannot be made, because "people are not fungible."[18] There are too many variables, she argues, to make a meaningful comparison about who has a better chance between, for example, her and her brother, she argues. She holds that it is misguided or futile to try to make "a comparison of myself and my nondisabled brother Mac (the next-born after me), each of us with a

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[15] See, e.g., Parens and Asch, "The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations," S11, S13–S15; Adrienne Asch, "Why I Haven't Changed My Mind about Prenatal Diagnosis: Reflections and Refinements," in *Prenatal Testing and Disability Rights*, ed. Erik Parens and Adrienne Asch (Washington, D.C.: Georgetown University Press, 2000), 243–244; and Ron Amundson, "Disability, Ideology, and Quality of Life: A Bias in Biomedical Ethics," in *Quality of Life and Human Difference: Genetic Testing, Health Care, and Disability*, ed. David Wasserman, Jerome Bickenbach, and Robert Wachbroit (New York: Cambridge University Press, 2005), 101–124.

[16] See Section 2.6 below for more on the social aspects of disability and the danger of complicity with objectionable social norms.

[17] Johnson, "Unspeakable Conversations."

[18] Ibid.

combination of gifts and flaws so peculiar that we can't be measured on the same scale."[19] Johnson's line of thinking suggests, then, that any attempt at selection that aims to raise the likelihood that the resultant child will flourish would also be misguided or futile since prospective parents would base their selections on factors like presence or absence of a disabling or otherwise serious medical condition that is not predictive of quality of life. Beyond expressing an offensive attitude toward disability, Johnson's argument seems to suggest that selection against disabilities and serious medical conditions would not be effective in achieving its goal of increasing the chances for a rich, fulfilling life. Some empirical evidence seems to support her conclusion, since a number of studies of the quality of life of families with children with disabilities enjoy statistically similar levels of happiness and prosperity when compared with families with children who do not have disabilities.[20]

2.4 Reply to Johnson: Selecting a Person vs. Selecting a Genetic Trait

Even if Johnson is correct that having a certain trait—almost any trait—is no guarantee that a person will thrive or fail to thrive, it is not true that certain traits, including those that prospective parents might consider selecting against, have no effect on how likely it is that a person will flourish. For example, conditions that significantly limit a person's life expectancy significantly limit her ability to life a rich, full life in virtue of the fact that they reduce its expected and likely duration. And, conditions that

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[19] Ibid.

[20] Parens and Asch, "The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations," S7, S11.

require frequent time-intensive treatment interfere with a person's freedom to pursue her other interests, whatever they might be. Thus, even though it is not true that having a condition like Johnson's or a number of other medical conditions precludes a person from living a full, rich life, these conditions do make it more difficult and, on average, less likely for a person to flourish.

Notice, too, that Johnson mistakes a comparison about initial situations for a comparison of the worth of two people. To see this, consider the question of what, exactly, prospective parents are—and are not—selecting in different-child choices. Importantly, at the time of selection, prospective parents are not faced with fully realized people like Johnson and her brother Mac to choose between; they may only have information about a small number of variables on which to base their choice. Parents who must make a different-child choice will have access to some information about the genetic traits of the gametes, embryos, or fetus involved but not much. The many variables that distinguish fully realized persons like Johnson and her brother do not yet all *have* assigned values at the time that the prospective parents must make their choice, much less known values for those variables. Selection in this type of case is not a matter of selecting one *person* over another but rather is selecting the presence or absence of a mutation or other genetic factor. And, the effects of the presence and absence of a mutation that causes a serious disease or a disabling condition on the chances of flourishing are meaningfully comparable in a way that Johnson and her brother, admittedly, are not.

Unlike selecting, for example, a spouse or a new employee by interviewing and evaluating candidates, the prospective parents cannot possibly have enough information when they make their selection for their decision to be an instance of selecting a person. They have access to some information about the genetic make-up of the two embryos, but not nearly enough for them to have any clear sense of who the person will be who will develop from that embryo, if the process is successful. No person exists at the time of the selection for them to know, as those who worry about the so-called “non-identity problem,” which I return to below, have made quite clear. Even if the prospective parents had access to the complete genetic code of the two embryos—the genotypes—and reliable information about the probabilities of various phenotypes that a person with that genotype would have, not even that description or list of characteristics would amount to enough information to qualify as knowing the person who would be created.

Knowledge of characteristics cannot provide knowledge of who a person is or will be. Consider the prospect of choosing a best friend or a spouse by description. That seems like a terrible idea. No description of traits could ever do justice to the totality of a person. The description, however detailed and thorough, would be an impoverished snapshot. But, even that snapshot would be more than we usually get when it comes to having a child. It is not possible to pick what kind of person your child will be. Even full knowledge of the genotype would not tell us important things about who the person would eventually be, such as what experiences will shape them and what values they will prioritize in their own lives. So, when parents have children, they really do not know what they are going to get. Even if prospective parents could choose as many features as they like—sex, hair color, height, build, musical talents, athletic ability, and so on—they will still very likely to be surprised everyday by the unexpected personality traits and physical characteristics of their kids. It is not possible to deliberately control all of the genetic and environmental factors that make a person who she is.

If my argument above is correct, selection of embryos for implantation is not properly understood as selection of a person like Johnson or her brother Mac but rather as selection of some genetic characteristics. This is because at the time that the prospective parents make the decision about whether to select the totality of the person who might result from the selective choice does not yet exist in a fully realized form. Selection must be based only on some information about some genetic characteristics of some gametes, embryos, or fetuses. That limited information does not provide prospective parents with enough information for them to know the fully realized person whom their child might (eventually) be. This conclusion suggests that selection of gametes, embryos, or fetuses is quite impersonal, in a sense, since, at the time of the decision, there is no person yet to be affected. To be sure, selection is another sense quite personal in that it affects which person (eventually) lives. But, it determines which person will live based on a very limited amount of information about who that person will be: whether or not a genetic mutation is present that causes or is correlated with a disabling condition.

So, what are prospective parents selecting when they select an embryo without a genetic mutation over an embryo with that mutation? They are not selecting one person instead of another. They are not necessarily selecting to promote one group over another. They are not necessarily saying that any class of existing people is worth less or that they do not value existing people who have whatever traits that mutation corresponds to. If they, like Bonnie and Dan Rough, are acting from the motive of doing what is best for their children, then they are better understood as selecting what they take to be a less burdensome beginning instead of a more burdensome one. They are acting on a judgment that life is hard enough without the burden of suffering that could have been prevented, greater than average need for medical care, and/or reduced opportunities.

Some people, unlike the Roughs, *will* want to use selection to disvalue the disadvantaged or to act on their misguided view that certain classes of people—females, homosexuals, blue-eyed people, perhaps—are somehow lesser or undesirable. That would be wrong. But, just as I noted above when considering the initial implications of the expressive effects worry, it would not be wrong because it is selection. It would be wrong because it is done to further a bad end, not because it is bad in itself.

In summary, while selection against certain genetic mutations does include a value judgment about how advantaged or disadvantaged a child with that mutation's initial situation will be relative to other possible initial situations (of other possible children), it need not be a judgment about the worth or value of existing people with similar initial situations or existing people with the disabling conditions that the parents are selecting against. It need not, in fact, cannot, be a judgment about the particular possible children themselves, since all that is know about them are a few facts about their initial situations. Nothing is known of their personalities, the accomplishments they would have if created, the heartaches they would endure, their temperaments—that is, nothing personal. We cannot know possible persons as persons if they do not become actual persons. Thus, selection cannot be properly understood as necessarily containing in any way or expressing the judgment that a child born with a particular genetic trait is less valuable or deserving of respect as a moral equal to children with different traits. Rather, selection is properly understood as expressing a judgment about the relative burdens and challenges of having the relevant traits.

2.5 The Significance of the Selected Trait in Context

Even if I am right that selection is not properly a matter of selecting people or necessarily expressing a value judgment of the relative worth of people with and without certain condition but rather a matter of selecting a trait and expressing a judgment about the burdens and benefits that trait is expected to contribute to a newborn's initial situation, you might wonder how significant that difference is when it comes to the morality of selection. Am I splitting hairs? How significant is the difference between selecting between people and selecting between genetic traits? After all, in a different-child choice the choice of gametes, embryos, or fetuses without a certain genetic mutation has the direct effect of bringing into existence only people without the selected-against traits. And, that direct effect is well understood at the time of the decision.[21] So, it seems that it does not make much of a difference in terms of understanding the ethics of selection and the import of the expressive effects worry to point out, as I have, that selecting for or against a genetic trait is not identical to selecting one fully formed person instead of another.

I do not wish to make more of the distinction that it deserves. To be sure, selecting against a disability, serious medical condition, or any other genetic trait has the direct effect of selecting that only children without the targeted trait have a chance at coming into existence, assuming that the method of selection is effective. I recognize that. And I do not mean to say that selection is not wrong because it does not *aim* to harm existing people by implying that they are interchangeable, replaceable, or fungible but

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[21] I thank Pamela Hieronymi for raising this concern.

merely treats them as such as a foreseen but not aimed at consequence; I am not relying on any version of the Doctrine of Double Effect here.[22]

Recall that the expressive effects worry and Johnson's objection that selection sends the message that people are fungible focus on the *attitudes* expressed by selection about the relative value or moral worth of people with different disabilities, medical conditions, or other traits. With my distinction between selecting people and selecting congenital traits, I mean to challenge her interpretation that selection expresses a value judgment about types of people and suggest instead that it does not necessarily express anything more than a value judgment about the disadvantages or burdens of having certain congenital traits, including those that cause disabilities.[23] I want to acknowledge that there are burdens and disadvantages that are an inherent part of having a disability or serious medical condition, while rejecting the view that people with those disabilities or serious medical conditions have lesser value than those who do not.[24] Johnson objects that selection and its proponents are misguided, in part, because it treats people as the kinds of things that can be evaluated as more or less valuable when in fact there are too many variables to make any sort of meaningful judgment about the value of one person's life as compared with another. My response to her above aims to argue that she is wrong to draw her conclusion from her evidence because selection involves a value judgment

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[22] For an explanation of the Doctrine of Double Effect and a summary of problems with it, see Philippa Foot, "The Problem of Abortion and the Doctrine of Double Effect," *Oxford Review* 5 (1967), 5–15.

[23] I return to this latter value judgment at length below when I respond to the third prominent approach to the ethics reproductive selection, the non-identity problem approach, and how we can make sense of whether a person is better or worse off if they are born with or without a given trait. See Chapter 4.

[24] Cf. Parens and Asch, "The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations," S13.

only of the trait in question, not of any whole person who has that trait. It is a further question whether we can meaningfully make a value judgment about the presence or absence of the trait, and I will return to this question at length below. For now, however, I take myself to have shown that selection does not necessarily express that different people have different moral value or that people are fungible.

But, there is another point about my argument above regarding the difference between selecting a person and selecting a trait that calls for clarification and care. This point concerns the relationship between a person with a disability or serious medical condition and her trait of having that disability or condition. Especially when it comes to people with disabilities, it is important to exercise care when shifting from consideration of the whole person to consideration of the part of that person—the trait—that causes or constitutes the disability. This care is important because people with disabilities "daily experience being seen past because of some single trait they bear."[25] Much of the discrimination people with disabilities face takes the form of others viewing or treating them as nothing more than their disability. Rather than seeing Johnson as a successful lawyer and activist, for example, some people saw her as nothing more than, in her own words, "a jumble of bones in a floppy bag of skin."[26] As Adrienne Asch writes, "a single trait stands in for the whole[;] the trait obliterates the whole."[27] The trait of having spina bifida or HED or some other serious medical condition is a much more significant

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[25] Ibid., S2. See also Adrienne Asch, "Why I Haven't Changed My Mind about Prenatal Diagnosis: Reflections and Refinements," 234–258.

[26] Johnson, "Unspeakable Conversations."

[27] Asch, "Why I Haven't Changed My Mind about Prenatal Diagnosis: Reflections and Refinements," as quoted by Parens and Asch, "The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations," S2.

determinant of how a person with a disability or serious medical condition is viewed and treated by others than most traits like height or eye color. So, for example, having a disability affects how others will interact with you in our society much more than having detached instead of attached earlobes.

The trait that people with disabilities struggle not to be mistaken for is the very trait selection aims to prevent. So, when disability rights activists like Johnson object that selection treats existing people with disabilities in a way that is derogatory or disrespectful, merely noting that it is not the *person* who is necessarily being judged as less valuable but rather the *trait* that is being judged is not enough of a response. It is important to recognize this context of discrimination against people with disabilities as a crucial aspect of understanding the ethics of selection. The fact that people with disabilities are often disrespected by being treated as nothing more than their disabilities—as not whole persons—makes it crucial that we recognize and respect the limits on the significance of the fact that selection properly understood entails a value judgment about a trait and not any person. To ignore this context would contribute to or at least be complicit with the disrespect that should be rejected.

The reality for people with disabilities is that their trait of having that disability plays an outsized role in their identity, whether they want it to or not. Thus, having a disability or not having one is not merely having one trait or another, in the way we might have attached or detached earlobes, without any significant value attached to either option. When it comes to selection against a disabling condition, to target the trait is, in effect, to target the person, given the realities of the way that disability is viewed and discriminated against in our society. After all, in order for the trait of having a disability to be instantiated, there must be a corresponding person who has it. Unless and until we change societal attitudes and practices of discrimination against people with disabilities, we must take care not to be complicit in perpetuating them, even when our intentions are to do what is best for our children.

2.6 What We Learn from the Expressive Effects Worry about Selection

The fact that selection *could* be practiced for derogatory reasons does not entail that selection itself is necessarily derogatory. The expressive effects worry succeeds in making its case for selection being wrong because of the message it sends only in cases in which an objectionable message about the worth of existing people with disabilities is actually being sent. Selection need not entail any judgment that certain people have less worth than others or that their lives are not worthwhile at all; rather it entails a judgment about the relative value of having one trait—often a serious medical condition—instead of an alternative. Thus, while I certainly agree that the view that people with disabilities are not equal to other people is offensive and discriminatory, I do not find that selection is wrong because it expresses this view. In cases in which selection was used as an expression of that view, selection is wrong. But, not all cases of selection express that view.

Still, we must guard against complicity. Given the way people with disabilities are often treated in our society, the significance of disabling traits for those who have them must be acknowledged, and the ethics of selection should recognize the potential for discrimination and injustice. In this way, disabling traits resemble traits like sex and race or ethnicity, which also raise ethical concerns when we think about reproductive selection based on those traits. If we lived in a time and place in which skin color, sex, and disability status had no impact on social advantage or discrimination, then we might assume that parental preferences in these areas were benign and simply that, preferences. But, given the reality that people are discriminated against and treated as merely a single trait rather than as a whole person on the basis of these factors, we must take care to recognize that while prospective parents are selecting one trait over another when they make different-child choices, that selection takes place in a context of discrimination. Even if the parents do not intend to endorse that discrimination, their selection might be complicit in perpetuating it.

Banning selection or proclaiming it offensive, insulting, or harmful to existing people with the traits targeted for selection will not solve the cultural and institutional problem of discrimination. But, the expressive effects worry teaches us not to underestimate the potential for selection to contribute to the problem, whatever the motivations behind it. Even selection that is intended as an effort to prevent future children from suffering the offenses, insults, and harms that existing people endure—and, quite possibly, overcome—might contribute to perpetuating the attitudes and institutions that are responsible for those offenses, insults, and harms. This contribution is what I am calling complicity.

While a full account of this notion of complicity is beyond the scope of this project,[28] I want to offer the following thoughts about how to think about the ethical

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[28] For an excellent discussion of the notion of complicity with objectionable attitudes and practices in health care and the role of clinicians, see Margaret Olivia Little, "Cosmetic Surgery, Suspect Norms, and the Ethics of Complicity," in *Enhancing Human Traits: Ethical and Social Implications*, ed. Erik Parens (Washington, D.C.: Georgetown University Press, 1998), 162–176. I use the term "complicity" with Little's account of the concept in mind.

danger of complicity in the context of selection before I turn my attention to a very different approach to the ethics of selection. I hope I have shown that, while some cases of selection might be morally wrong because they express or are complicit with discriminatory attitudes toward people with disabilities, other cases of selection are not morally problematic in this way. One way to tell the difference is to consider why it is a burden or a disadvantage to have a certain trait. If it is purely for cultural and institutional reasons, then the main problem is with the culture and its institutions, not with the trait. Here I have in mind traits like having dark skin, being a member of the female sex, and, deafness since these traits are only disadvantages in societies that are set up in such a way as to allow them to be. For traits in this category, efforts to select against those traits are complicit in the problematic attitudes and institutions. Instead of trying to prevent the creation of people who will suffer from these unjust attitudes and institutions, that effort would be better spent fighting against the injustice. That is not to say that it could never be permissible to select against traits in this category if, say, the burdens were great and the attitudes and institutions intractable. But, the issue of complicity is relevant here and must be included in the overall moral assessment.

If, instead, it is a burden or a disadvantage to have a certain trait for reasons that are purely independent of culture and the institutions of a society, then it is plausible that parents could want to prevent their children from bearing those burdens without anything discriminatory going on. Selection aimed at preventing a short, painful life due to Tay-Sachs disease, for example, does not raise concerns about discrimination or complicity with problematic attitudes and institutions at all. Traits in this category are clearly negative for those who have them, and selection against these severely limiting, painful conditions does not express negative attitudes about those who suffer from them, as even some disability rights advocates concerned about the expressive effects worry agree.[29]

The hard cases are, of course, the mixed ones, cases that are not purely institutionally or culturally created like racial or sex-based discrimination but not purely physical like Tay-Sachs disease either. And, that is why many of the cases involving disability are so hard. Both elements contribute to what makes it a disadvantage or a burden to have many disabilities. Concern about the expressive effects of selection teaches us that we *do* need to guard against outright discrimination and also complicity to the extent that disabilities are only a disadvantage when society is set up in such a way as not to accommodate them. But, there is also some truth to the idea that there are burdens or disadvantages to having a disability that are genuinely physical or mental or emotional and not fixable by society, and it seems permissible for at least some prospective parents to want to spare their children those burdens and disadvantages by means of selection when they can. The difficulty of these cases lies in determining, for some particular trait, whether selection on that basis is discriminatory, complicit, and/or compassionate and how those factors contribute to an overall moral judgment.

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[29] See e.g., Parens and Asch, "The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations," S11, S13, and Adrienne Asch, "Reproductive Technology and Disability," in *Reproductive Laws for the 1990s*, ed. Sherrill Cohen and Nadine Taub (Clifton, N.J.: Humana Press, 1989), 73.

Chapter 3

The Moral Obligation to Create Only Children with the Best Chance at Flourishing and the Moral Obligation to Accept One's Children As They Are

3.1 Two Competing Parental Obligations

One of the ways in which different-child choices generate a moral dilemma arises because of a tension between two competing moral obligations that prospective parents seem to have. In cases in which assisted reproductive technology allows parents to have some control over—some choice about—which embryos they do and do not encourage to form, implant, and grow into children, these competing moral obligations seem to require different, mutually exclusive, courses of action.

First, prospective parents should—and tend to want to—do what they reasonably can to provide the best chances for their children to thrive. The desire to maximize one's children's health is, in general, admirable. It is a good thing when parents want to give their children the healthiest start in life that they can. This desire leads parents to do things like seek prenatal medical care and to take measures to provide a safe and stable environment for their children.

On the other hand, parents have an obligation to love and accept their children whatever their health status is. So, once a child is born with a medical condition, even a serious medical condition, prospective parents should recognize that they as parents ought to accept that child as she is once she enters their lives. They, of course, still ought to do what they can to help her thrive to the extent possible given her condition and available resources, but it would be wrong of them, say, to reject a baby after birth due to her health status in favor of replacing her with a different, healthier child.

So, in the context of a different-child choice, which obligation wins out? Should parents take advantage of technological advances that allow them to select the gametes or embryo that will have the best chance at a good life? Should they leave it up to chance, acknowledging the importance of acceptance and unconditional love in good parenting? Does it matter? On what does it depend? In this chapter, I take up each of these two purported parental obligations in turn and then offer analysis of the tension between them.

3.2 The Moral Obligation to Select Children with the Best Chance at Flourishing

Consider a severe, devastating medical condition like Tay-Sachs disease. Tay-Sachs disease is a genetic condition that is transmitted following a single gene autosomal recessive pattern. This means that if two prospective parents are both carriers—heterozygous for the mutation that causes Tay-Sachs disease—then their offspring each have a 25% chance of inheriting the deadly combination of two mutations that will cause Tay-Sachs disease. Tay-Sachs is "a fatal cerebral degenerative disorder"[30] that, shortly after birth causes blindness, deafness, an inability to swallow, muscle atrophy, paralysis, seizures, dementia, a pronounced startle reflex, and a life expectancy of no more than four years.[31]

Sufferers of such devastating conditions such as Tay-Sachs disease who have no

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[30] John S. O'Brien et al., "Tay-Sachs Disease: Detection of Heterozygotes and Homozygotes by Serum Hexosaminidase Assay," *New England Journal of Medicine* 283.1 (1970), 15.

[31] National Institute of Neurological Disorders at the National Institute of Health, "NINDS Tay-Sachs Disease Information Page," http://www.ninds.nih.gov/disorders/ taysachs/taysachs.htm.

hope of treatment or of attaining a bearable quality of life are said to have lives that are not worth living, and the creation of such lives sometimes qualifies as wrongful creation of life, at least legally speaking[32] and probably morally speaking as well. If prospective parents could prevent a child from suffering the pain, burdens, and suffering associated with such a devastating condition, it seems plausible that they ought to do so. When it comes to conditions such as these whose sufferers have no hope for any experience other than pain and an early death and there is no available treatment that can alleviate that suffering and offer some possibility of an acceptable quality of life, it is hard, if not impossible, to see any good reason for prospective parents to allow a baby to be born to suffer that fate if it is possible to avoid it. Thus, there seems to be an obligation on the part of prospective parents to take reasonable measures to avoid creating children with the most severe medical problems and disabilities.

Following this logic a step further, it seems plausible that there might be an obligation to take advantage of preconception screening or targeted genetic testing to evaluate a particular couple's risk levels and even an obligation to make use of IFV with PGD or selective termination of pregnancies, at least when there is a significant risk of passing on a condition that would significantly reduce a child's likelihood of living a good life. Absent some reason to restrict this sort of selection to only the most severe conditions, perhaps the obligation to use these tests and selective technologies extends to conditions of moderate or mild severity or, even further, to cases in which selection could

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[32] For insightful discussions of the ethics of creating a child whose life is not worth living or worth not living and the legal notion of wrongful life, see Seana Valentine Shiffrin, "Wrongful Life, Procreative Responsibility, and the Significance of Harm," *Legal Theory* 5 (1999), 117–148, and Jeff McMahan, "Wrongful Life: Paradoxes in the Morality of Causing People to Exist," in *Bioethics*, ed. John Harris (Oxford: Oxford University Press, 2001), 445–475.

be used to create only the most advantaged—or even enhanced—offspring. This line of thought forms the basis of the approach to the ethics of reproductive selection taken by philosophers and bioethicists such as John Harris, Julian Savulescu, and Guy Kahane. According to their approach, prospective parents have an obligation to take advantage of opportunities to screen, test, and select so as to create only those children who are most likely to thrive.

Savulescu has coined the term "parental beneficence" for this obligation.[33] He and Kahane claim that prospective parents for whom selection is possible "have a significant moral reason to select the child, of the possible children they could have, whose life can be expected, in light of the relevant available information, to go best or at least not worse than any of the other;" this is their "Principle of Parental Beneficence."[34] They argue that prospective parents ought to care about their future child's well-being and that it would demonstrate a "moral defect"[35] on the prospective parents' part if they were indifferent to the likelihood that child would experience a good life. From the fact that prospective parents have reason to care about their future children's likelihood of experiencing a good life, Savulescu and Kahane conclude that the prospective parents "also have reason to *aim* to have children who are more advantaged rather than leave this to chance or nature."[36] To support this claim, they point to Derek Parfit's case of a woman who, if she conceives now, will have a child with a serious medical condition, but who, if she waits a

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[33] Julian Savulescu, "Procreative Beneficence: Why We Should Select the Best Children," *Bioethics* 15.5/6 (2001), 415.

[34] Julian Savulescu and Guy Kahane, "The Moral Obligation to Create Children with the Best Chance of the Best Life," *Bioethics* 23.5 (2009), 274.

[35] Ibid., 276.

[36] Ibid. Emphasis theirs.

few months, will conceive a child without that condition.[37] According to Savulescu and Kahane, it is uncontroversial that a woman in this situation ought to wait before she attempts to conceive a child,[38] and they think that that same reasoning applies to other ways that prospective parents can improve their future child's prospects for a good life. They classify reproductive selection in the same category as waiting for a rubella outbreak to pass, taking steps to shore up financial resources, and selecting a genetically promising mate before trying to conceive.[39] For them, all of these activities contribute to a familiar and long-recognized parental obligation to promote their children's well-being. Recent technological advances merely give us new ways to fulfill this obligation by selecting those gametes, embryos, or fetuses that have the best chance of the best life, according to this view.

By including the clause "of the possible children they could have" in the statement of their principle of parental beneficence quoted above, Savulescu and Kahane acknowledge that this requirement must be relative to what possible children there could be for any given couple. If, for example, it is only possible for two prospective parents who are both deaf to conceive deaf children because both parents have two Connexin 26 mutations associated with autosomal recessively transmitted deafness, then Savulescu and Kahane hold that it is permissible for them to have deaf children. Any requirement to

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[37] Derek Parfit, *Reasons and Persons* (Oxford: Oxford University Press, 1986), 367.

[38] Savulescu and Kahane, "The Moral Obligation to Create Children with the Best Chance of the Best Life," 276. But, see Dan Brock's "Is Selection of Children Wrong?" in *Human Enhancement*, ed. Julian Savulescu and Nick Bostrom, (Oxford: Oxford University Press, 2009), 252–253, for his report of disability rights activists who dispute this very claim.

[39] Savulescu and Kahane, "The Moral Obligation to Create Children with the Best Chance of the Best Life," 276.

select against this form of deafness to give their children better chances at a good life[40] does not to apply to this couple since their biological children cannot avoid inheriting two copies of the mutations that cause this form of deafness, at least given the state of current technology. However, for prospective parents who are heterozygous for these same Connexin 26 mutations (and are aware of their carrier status[41]), Savulescu and Kahane hold that there is moral reason for these parents to select against deafness since it is possible for this couple to create hearing children who would have a better chance at the best life than their potential deaf siblings.[42] Thus, the comparisons Savulescu and Kahane require prospective parents to consider are between the children it is possible for a particular set of prospective parents to create and not between their own possible children and all existing and possible children.

For John Harris, in addition to Savulescu and Kahane, in a situation that requires a different-child choice, such as when prospective parents conceive using IVF and have more embryos available than it would be safe to implant at one time, those prospective parents ought to select the embryo or embryos "that will have the best possible chance of

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[40] The notion that deafness necessarily decreases a person's chances at living the best life is controversial, and I do not want to take a stand in that debate. I do think it is clear that Savulescu, Kahane, and others who appeal to an obligation of parental beneficence to argue the selection is morally required would judge that a hearing child would have a better chance at the best life than a deaf child, based on their discussion of how we ought to judge the chances at living a good life, which I discuss below.

[41] For more of a discussion of the relationship between awareness of risk and the permissibility of created an affected child, see Chapter 5.

[42] Savulescu and Kahane, "The Moral Obligation to Create Children with the Best Chance of the Best Life," 275. While Savulescu and Kahane here explicitly reject the view that prospective parents who cannot conceive children without serious medical conditions should not have any children at all and they do not seem to think prospective parents in this situation have strong reason to use gamete donors or adopt in order to give their children an even better chance at the best life than any of their own possible biological children could have, they do not give an argument for why they draw the line where they do. They claim prospective parents should create only those children among the possible children they can create, but they do not give an argument for why this requirement would not extend beyond current methods for conceiving their own biological children.

a long and healthy life."[43] Harris reaches this conclusion by arguing that to choose otherwise would be morally objectionable. To choose to implant only embryos that are expected to have a lower relative chance at a long, healthy, fulfilling life would require the belief that it makes no moral difference whether the child inherits a genetic medical condition or not when the parents are in a position to prevent it. And, Harris claims—rightly, I think—that this belief is implausible. Thus, Harris argues, since choosing to implant embryos that are expected to have a lower chance of a long, healthy life requires a false belief about the moral relevance of inheriting a preventable condition, prospective parents ought to select from among the embryos with the greatest expected chance of a long, healthy life.

However, Harris's move from noticing that (a) the act of choosing to implant embryos that we know to have worse chances at flourishing fails to demonstrate due concern for one's children's well-being to the conclusion that (b) prospective parents ought to choose only those embryos with the best possible chances is too quick. There is more to the moral landscape here. For starters, there is at least one other parental obligation besides the obligation to promote one's children's well-being that must be considered here if we are to fully assess the morality of different-child choices. Beneficence is not the only parental virtue, and it cannot be an absolute requirement that parents always maximize well-being since other considerations are relevant to the question of what is required for good parenting.

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[43] John Harris, "One Principle and Three Fallacies of Disability Studies," *Journal of Medical Ethics* 27.6 (2001), 385.

3.3 The Moral Obligation to Accept One's Children As They Are

Recall two of the moral worries I raised in Chapter 1. First is the worry about whether prospective parents have the rightful authority to decide which children are created and which are not on the basis of the presence of absence of a genetic trait. Second is the worry that prospective parents might fail to be good parents by being too choosey about which traits they judge to be unacceptable or undesirable in their offspring. It seems crucial to determining the morality of selection to note that there seems to be a parental obligation of acceptance. As part of being good parents, people should accept their children for who they are, whatever their traits. They ought not overstep their authority by trying to control who lives and who never has a chance to be created. This requirement of acceptance thus seems inconsistent with efforts to select only children who have (or do not have) certain traits or to seek to control which traits they do and do not inherit at all. If an essential part of parents' proper role is to accept whatever children they create, then it seems that they should not to put limits on which traits they find acceptable. From this line of thinking, it follows that parents should not select in different-child choices, but rather they should accept whichever child with whichever traits they create by chance. They should love and accept their child unconditionally, and attempts to control which types of children will be created or to design babies demonstrate a failure to live up to that parental obligation.

Michael Sandel argues for the importance of this parental requirement to accept one's children as they are by making use of a distinction between transforming and accepting love.[44] What I discuss above as the parental obligation to create children with the best chance of the best life could be understood as involving primarily transforming love, while the parental obligation to accept one's children as they are can be understood as a form of accepting love. Transforming love is a form of love that is directed toward encouraging its object to grow, develop, and improve; it "seeks the well-being of the child."[45] Efforts to give children access to good schools, sports and music lessons, preventive health care, and good nutrition all fit into Sandel's category of parental attempts to demonstrate transforming love toward their children.

In contrast, Sandel describes accepting love as love that is not directed toward any further aim of changing or improving its object.[46] Whereas transforming love, as its name suggests, aims to transform its object, accepting love accepts its objects as they are, without any further agenda. It is in this sense unconditional; it does not depend on its object having (or lacking) any specific traits or achieving any goals. This attitude of accepting love that Sandel describes seems to be in line with the sort of love that Leo Kittay argues is necessary for healthy family relations.[47] Recall that Kittay argues that without acceptance of whatever traits family members happen to have, a family becomes more like a club with membership criteria that require members to have certain traits and excludes those who do not fit that profile. This introduction of membership criteria,

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[44] Michael Sandel, "The Case against Perfection: What's Wrong with Designer Children, Bionic Athletes, and Genetic Engineering," *The Atlantic Monthly*, April 2004, http://www.theatlantic.com/past/docs/issues/2004/04/sandel.htm. He credits this terminology to William F. May, a theologian.

[45] Ibid.

[46] Ibid.

[47] Kittay with Kittay, "On the Expressivity and Ethics of Selective Abortion for Disability: Conversations with My Son," 169–170.

Kittay claims, erodes the important sense of acceptance and belonging in both family members who do not meet the criteria and in those who do, as they recognize that their acceptance is contingent on their have the approved traits.

Sandel offers a moral argument against reproductive selection (and various forms of enhancement, which are Sandel's main topic) based in large part on this distinction between transforming and accepting love. For Sandel, the obligation to accept one's children as they are requires that parents refrain from choosing which children one creates and which traits will be selected for or against. Because, in his view, "[p]arental love is not contingent on the talents and attributes a child happens to have,"[48] trying to control the traits one's child may and may not have demonstrates a morally objectionable disposition. He argues that reproductive selection overemphasizes the transforming attitudes of parental love while failing to demonstrate properly accepting love. Selection, according to Sandel, is inconsistent with a properly accepting attitude toward parenting and toward one's future potential children.

I disagree with Sandel's conclusion for the same sort of reason that I find accounts like those offered by Harris, Savulescu, and Kahane incomplete. I think Sandel is right that there is an illuminating distinction between transforming and accepting love here, and I agree that prospective parents must find the right balance between the two. However, while I find this distinction helpful for pinpointing a tension between parental obligations in different-child choices, I reject Sandel's conclusion that selection is necessarily a failure of acceptance. I see no reason why prospective parents could not consistently choose to select against a certain condition, yet welcome an affected child

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[48] Sandel, "The Case Against Perfection."

into their family with full acceptance if the effort to select is unsuccessful. As I argue in the next section, due to the complexity of the relationship between these two forms of love within the parent-child relationship, reproductive selection is not necessarily a failure to satisfy the obligation of parental acceptance, because the obligation to accept one's children as they are is not absolute and is not without limits.

3.4 A Closer Look at These Two Purported Parental Obligations

Both of the two purported parental obligations described above—to take reasonable measures to ensure that children will have the best possible chance to live the best possible life and to accept children as they are, whatever traits they have—seem to me to be plausible candidates for obligations that parents must meet, all other things being equal, in order to be good parents. However, there are some significant difficulties in making sense of the content and force of these obligations that merit a closer look.

The main difficulties with making sense of the obligation to create children with the best chances of the best life lie (1) in specifying how better and worse chances at living the best life can possibly be determined by information about genotype alone and (2) in problems with making sense of a requirement that parents to aim for the *best life* for their children. I take these two difficulties up in turn.

The details about how to compare the expected chances of living a good life between possible siblings are difficult, if not impossible, to work out. How ought we to make these comparisons? At the extremes there are some genotypes that are clearly worse to have than others, such as those that are homozygous for Tay-Sachs disease. So, if we dramatically limit our interpretation of better and worse to only include free from and affected by a devastating genetic disease, then it seems clear how we can make such comparisons, at least to the extent that currently available testing can determine the presence or absence of those conditions. But, this dramatically limited interpretation of the "best chance of the best life"[49] is a far cry from what proponents of the parental beneficence obligation seem to have in mind, though. For their approach to determining which children to create, which embryos to implant, or other forms different-child choices to be workable, there must be a way to make finer-grained comparisons between different possible children beyond just comparing those who will certainly develop a devastating condition and those who will not. But, it is not clear how to calculate the chances most of us have at living a good life on the basis of our genetic code or how to compare those odds as better or worse. Which is worse, an elevated risk of contracting breast or ovarian cancer in middle age or an elevated risk of developing a serious but non-fatal mental health condition? I, for one, do not know, and I do not see a promising way to go about finding out.

In large part, the information we can obtain by means of pre-conception or prenatal testing provides and incomplete picture of the significance of genetic traits, and the information is often data about levels of risk rather than certainties. Even as our ability to interpret that information improves as our understanding of genetics progresses, we must recognize that comparisons between possible children would require us to make judgments about the relative badness of a wide range of conditions that can manifest in an unpredictable wide range of severities. We have a daunting, if not impossible, task of

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[49] Savulescu and Kahane, "The Moral Obligation to Create Children with the Best Chance of the Best Life," quoting from the title of the article.

quantifying and comparing chances of flourishing, if we are to create only those children with the best chance at the best life. So, unless we dramatically restrict our interpretation of better and worse to mean the absence or presence of a known mutation for a serious genetic condition, it is unclear how well we can assess the chances at a good life on the basis of genetic information alone.

In response to this type of objection to the parental beneficence account, Savulescu and Kahane point out that we do have a working grasp of what is better and worse—within a pluralistic understanding of what it is to life a good life—even if we do not have a fully worked out theory.[50] They suggest that we rely on this working grasp of better and worse chances to make the necessary comparisons. While I agree that we *do* tend to have such a working grasp of what traits make it more or less likely that a child will have good chance to flourish, I worry about making decisions about selection in different-child choices on the basis of those judgments. Unexamined, those judgments are likely to be discriminatory and just plain incorrect. Before such judgments can be made reliably and well, we would need a non-discriminatory and accurate understanding of how various genetic traits contribute to an individual's chance at living not merely an acceptably good life but the best possible life. Genetic traits alone do not determine an individual's expressed characteristics, and interactions among various genes along with myriad environmental influences create a highly complex, probabilistic relationship between an individual's genotype and phenotype. Savulescu and Kahane fail to respect this complexity when they suggestion that our working grasp of what genetic traits

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[50] Savulescu and Kahane, "The Moral Obligation to Create Children with the Best Chance of the Best Life," 278–279.

correspond with better and worse chances at flourishing can function as an adequate, reliable basis for such judgments.

Unlike Savulescu and Kahane, Harris argues that prospective parents have an obligation to select without requiring them to make overly demanding, perhaps impossible, comparisons between genotypes. He manages this not by going to the dramatically limited interpretation of better and worse chances at flourishing that I considered first, but by setting up a different dichotomy instead of the kind of scale from worst to best that Savulescu and Kahane's picture seems to require. For Harris, the "worse" category of possible children that prospective parents have reason to select against when they can are those with genotypes associated with any "condition that someone has a strong rational preference not to be in and one that is in some sense a harmed condition"[51] where by "harmed" he means worse off than a possible alternative that someone else might enjoy and not necessarily worse than a previous or even possible state for that same individual. The category of "better" conditions would include all of the other possible children for those prospective parents.

For Harris, then, the difficulty lies in specifying which conditions it is rational and irrational to prefer not to have. Again, it seems clear at the extremes, and, again, we do have a working grasp of which conditions fit on which side of the line. But, that working grasp is controversial, and for many conditions it could be rational for one person to prefer not to have a particular condition but irrational for another. Without a plausible, more fully worked out notion of what genetic profiles constitute better and worse chances at flourishing, accounts of the ethics of reproductive selection based on a parental

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[51] John Harris, "One Principle and Three Fallacies of Disability Studies," 384.

obligation to create children with the best chance at flourishing cannot offer guidance for the hardest cases, since those cases are exactly the ones in which it is not clear if it is worse for a child to be created with a serious but not extreme condition that is compatible with flourishing but perhaps decreases the chances of it.

In trying to make sense of the obligation to create children with the best chances of the best life, there are also problems with the notion of the "best life." Savulescu and Kahane—rightly, I think—specify that this phrase ought to be understood pluralistically; they reject the notion that there is any one way to live well.[52] But, does talk of an obligation to create children with the best chances of the best life suggests that prospective parents must only create children who have a good chance at an amazing life? This seems much too strong. If only the best ought to be created, then the human race ought to have died out long ago since no children should have been born into poverty, famine, or conditions of warfare or even political instability. Presumably the "best life" would not only lack these major environmental hardships but also more minor discomforts or health problems. If a possible child has a high probability of suffering from an itchy, flaky scalp, say, that seems worse than not having to endure that nuisance, so are we to conclude that such a child should not be created because she has no chance of living the very best life? That seems silly, to be sure, but it is not immediately clear how to interpret the notion of the "best life" if not in this most literal way.

Perhaps there is something of a minimal standard below which parents fail to meet their obligation to provide children with the best chances at flourishing. That

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[52] Savulescu and Kahane, "The Moral Obligation to Create Children with the Best Chance of the Best Life," 279.

interpretation explains why it seems impermissible to knowingly create a child with a condition as devastating as Tay-Sachs disease. But, if that is all there is to this parental obligation, then calling it an obligation to select or create children with the *best* chances at the *best* life is a gross overstatement of the content of the obligation.

Perhaps instead “best life” ought to be understood as the best life within the range of possibilities for a particular set of prospective parents, as long as at least some of those possibilities meet or exceed a minimal standard. So, if it is only possible for a particular couple to conceive children who will have an autosomal recessive condition that is uncontroversially worse to have than not to have because the parents themselves have it and are homozygous for the relevant mutation, then it is permissible for those parents to conceive such a child even though it would violate the obligation of parental beneficence for a couple capable of conceiving both affected and unaffected children to allow an affected child to be created.

But, why stop there? If it is within the first couple’s control to prevent the creation of an affected child—which it may well be by careful use of effective birth control and termination of any unplanned pregnancies—then perhaps the obligation of parental beneficence requires the affected couple to refrain from creating any biological children of their own at all since they could give a better start to an adopted child or a child conceived using donated gametes. This interpretation of the obligation seems to suggest that, for any prospective parents whose own genetic make-up is anything less than ideal, creating their own biological children would violate the obligation since other gamete sources would provide a better chance at the best life.

This interpretation that requires at least some prospective parents to create children using gametes that are not their own goes beyond even Savulescu and Kahane's stated view. They expressly reject the interpretation of the obligation according to which "people should have no child at all rather than one who is less advantaged than other existing children."[53] They seem to draw a line at requiring prospective parents to adopt or seek "better" genetic sources than their own, but why? Presumably proponents of the obligation of parental beneficence believe that this interpretation goes too far in limiting procreative liberty. While a full analysis of how successfully the case can be made for limiting the obligation of parental beneficence so as to protect prospective parents' freedom to create children with whom they have a biological connection and the role of biological connections in family relationships is beyond the scope of this project, I want to flag the fact that proponents of accounts based on parental beneficence owe an argument here.

The most plausible interpretation of Savulescu, Kahane, and Harris's notion of "best life," then, seems to be the best life within the range of biological possibilities for a particular set of prospective parents, as long as at least some of those possibilities meet or exceed a minimal standard. Notice, though, that it is highly likely that for each of us there existed one of our parents' other, merely possible children who had a better chance at the best life than we did when we were created.[54] Maybe there was a possible child my parents could have conceived during the months my mom was pregnant with me who

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[53] Ibid., 275.

[54] A similar point is discussed by McMahan in "Preventing the Existence of People with Disabilities," in *Quality of Life and Human Difference: Genetic Testing, Healthcare, and Disability*, ed. David Wasserman, Jerome Bickenbach, and Robert Wachbroit (New York: Cambridge University Press, 2005), 159–161, by Jonathan Glover in "Future People, Disability, and Screening," 435–436, and by John Harris in "One Principle and Three Fallacies of Disability Studies," 385.

would have found a cure for certain types of cancer or prevented a war or done any number of exceptional things that would have been much better than anything I have or ever will accomplish. Maybe one of my merely possible siblings would have attained a form of spiritual enlightenment that I will not. Almost certainly there exists a different combination of my parents' DNA that would have produced a different child who would have had greater talents or a greater likelihood of thriving in her environment to a greater degree than I have.

No one (or almost no one) started off with the best chance at the best life, even relative to what range of children it was possible for our parents to create. If we were to accept the (admittedly problematic) idea that it is possible to rank different genetic inheritances on a scale from best to worst chances at the best life, then accepting that there is an obligation for parents to create the children with the best seems to require that all (or almost all) parents have failed to meet this obligation. That conclusion makes the argument for the existence of this obligation look like a reductio ad absurdum.

The more I try to specify the scope and content of the parental beneficence obligation, the harder it seems to be to pin down. There is good reason to doubt that genotypes can be meaningfully translated into comparable values that can be compared and ranked as more and less likely to lead to the best life, and the notion that parents have an obligation to only create children with the best chances for the best life is overstated. But the parental beneficence obligation is not the only obligation on the table, and it is also not the only one that is problematic. I turn my attention now to some problems that arise when trying to specify the details of the purported parental obligation to accept one's children as they are. In the next section I offer my take on what this discussion of these two purported obligations and the difficulties with them shows about the ethics of selection.

The purported parental obligation to accept one's children as they are clearly has limits. No one can plausibly believe that, in order to be good parents, parents ought to accept their newborn's inability to speak, walk, and talk as just part of who they are. Good parenting also requires nurturing and encouraging children to develop new skills. Similarly, if a child gets sick or injured, it would be bad parenting to "accept" that situation and stand idly by without trying to help the child recover. There are plenty of precautions, preventive measures, and treatments we expect parents to pursue rather than just "accept" whatever illnesses or injuries befall our children. Thus, the parental obligation of acceptance, like the parental beneficence obligation, cannot be an absolute requirement but rather ought to be considered as one among multiple considerations that contribute to what makes for good parenting. I do not take this general point to be controversial; acceptance is not the only virtue of good parenting.

With respect to selection in particular, though, Sandel suggests that the desire to select and efforts aimed at selecting which children will be created amount to failures to demonstrate adequate acceptance. Does selection necessarily exhibit non-acceptance? Is it relevantly different from the preventive measures and treatments that we think parents ought to pursue to protect, restore, or improve their children's health, and, if so, how? On the one hand, it seems clear that parents must *not* take an attitude of acceptance toward injuries, illnesses, and vulnerabilities to health problems when health care is available and can improve a child's health. Yet selection similarly aimed at improving the health of children raises worries about improperly trying to control the traits children have, failing to treat them with proper acceptance, or treating them as things to be designed and manipulated rather than welcomed on their own terms. What could explain a moral difference between the two types of actions?

I argue that the worrisome difference between treating or preventing a medical condition and selecting to prevent one is not that the former demonstrates due acceptance and the latter does not. Rather, the difference is that one is a same child choice, and the other is a different-child choice. Preventing or treating the condition seems like good parenting because it is a way of taking good care of a particular child. These actions in no way change which child is brought into existence, though it is worth noting that preventing or treating a serious medical condition will have effects on how that same child develops and on what identity-shaping life experiences she has. But selection is a different-child choice, selecting to create *this* unaffected child instead of *that* affected one. While both types of actions aim to prevent or treat a serious medical condition, the way they do it are different. One prevents or treats the condition while preserving the child, while the other prevents the disease by preventing the existence of the child who would have it. That difference seems morally significant.

According to its best interpretation, the worry that selection might fail to demonstrate due acceptance of one's children as they are, then, is less about accepting a particular child's *traits*, whatever they might be, and more about accepting the *child*, whichever child she may be. The parental obligation of acceptance counts against choosiness in parenting. Parents ought not to be selective about which children they will and will not accept, though they also ought to promote their children's well-being even in transformative ways. They must, however, stop short of trying to transform one child into a completely different child or to replace one child with another.

But there is a danger inherent in an approach to understanding the ethics of selection in different-child choices that focuses too much on this parental obligation of acceptance. This approach—as well as approaches that focus too much on the effects of selection on existing people with medical conditions—implies that all selection is necessarily morally wrong. Overemphasis on the obligation of acceptance leads to a conclusion that selection is wrong because it necessarily fails to be accepting. But, even if we grant for the sake of argument that selection does necessarily fail to be accepting, as we have seen, acceptance is not the only morally relevant consideration. Paying attention only to acceptance precludes attending to those other relevant considerations. Thus, there is a danger that focusing solely on acceptance could lead to a reckless approach to parenting.

How could it be reckless for prospective parents to refuse to select or even consider selection out of a commitment to accepting any child they might conceive? For many, if not most, prospective parents it would not be reckless. But, I claim, there are prospective parents who would act recklessly by refusing to select, even out of such a commitment to acceptance. Situations in which prospective parents know and understand that they are at high risk of conceiving children with a condition that is among the most severe, most painful, and most devastating, for example, fit in this category. To knowingly risk conceiving a child whose only experiences will be of severe pain and suffering when such births could be prevented by selection is not an admirable act of accepting love but rather a reckless act that may—or may not—result in an innocent being to coming into existence only to suffer.[55]

The class of situations in which it would be reckless for prospective parents to conceive *without* making use of available selective options might extend beyond this most extreme case, though I think the situation I describe is the most clear. Perhaps it would also be reckless to refrain from selecting against less devastating conditions when the prospective parents are unable to provide for a child with the relevant condition, whether because of financial, emotional, social, or other factors. It might be reckless to refrain from selecting against even moderate conditions if the means of doing so themselves are not especially difficult, expensive, or morally significant. Delineating the boundaries of the category of situations in which it would be reckless *not* to select is beyond the scope of this project, but I take it that that category includes at least some possible situations. Further, my guess is that its parameters might broaden as new methods of selection that are less burdensome or less morally controversial or both are developed.

3.5 What We Learn from the Two Competing Parental Obligations

The two parental obligations discussed in this chapter—to take reasonable measures to ensure that children will have the best possible chance to live the best possible life and to accept children as they are, whichever children with whatever traits they might have—conflict in different-child choices. If prospective parents ought to do what they can to provide their children with the best chances of flourishing, then it seems that they ought to take advantage of assisted reproductive methods when these techniques

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[55] I return to the topic recklessness in different-child choices in Chapter 5.

allow them to select against serious and detectable medical problems for which the prospective parents are at a known, significant risk of passing on to their offspring. But, selecting against serious and detectable medical problems in these ways seems to require rejecting specific offspring in favor of other offspring, which seems to violate the parental obligation to accept one's children whomever they may be.

Neither the obligation to create children with the best chances at flourishing nor the obligation to accept your children as they are could be an absolute obligation since the two can conflict, as they seem to do in different-child choices, and they are only two of the multiple requirements on parents, no one of which consistently trumps the others. Neither of the two discussed here seems plausibly more stringent of an obligation than the other across the board. Further, there are conceptual problems that make an accurate specification of the scope and content of these obligations difficult. So, attending to just one or the other of these two obligations cannot provide a complete answer the question of how to be a good parent or how to do what is best for your children in the context of a different-child choice. In order to resolve the tension between these two obligations in any particular different-child choice, prospective parents must find a proper balance between the competing aims of promoting their children's well-being and loving them in a genuinely accepting manner. In order to understand the ethics of selection in different-child choices, it is necessary to include these obligations among the relevant considerations, but neither one on its own nor even both together are sufficient for a complete account of this complex subject matter.

Chapter 4

The Non-Identity Problem

4.1 The Non-Identity Problem

Prima facie, creating a child with a serious medical condition seems to be clearly a bad thing for that child if the parents know ahead of time that she will have that condition and they have the option to prevent it but do not exercise that option. But, if the only way to prevent the medical condition is to have not the child who would be affected but a different child instead, then it is difficult to make sense of how being affected is a bad thing *for the child*. Which child is it bad for? In a different-child choice, the only available options are having one child—call her Alice—with a medical condition or having a different child—call him Alex—without that condition. In these cases, it seems that we cannot harm or wrong anyone in particular whether we create Alice or Alex. Either Alice comes into existence with her medical condition, or Alex comes into existence without it.

If the only way for Alice to be created is with a serious medical condition, then either she exists with it or she does not exist at all. Thus, it is odd to think that having a serious medical condition is bad *for Alice* since her only alternative is nonexistence. If her condition is compatible with having a life worth living, then living with the medical condition is better than nonexistence. Living a worthwhile life is better than not living a life at all.

But, the child, Alice, who, if created, would start off life with a serious medical condition, is not identical to the child, Alex, who, if created, would start off life without that condition. So, there is no single, particular individual who will be better or worse off as a result of any particular different-child choice. One child will come into existence, and one (or more) will not. For Alice, the possibilities are that she will exist with a serious medical condition, or she will not exist. For Alex, the possibilities are that he will exist without that condition, or he will not exist. We can ask which option is better or worse *for Alice*, and we can ask which option is better or worse *for Alex*. But, if we try to compare Alice's existence with Alex's existence in terms of which would be better for *the* child, we are trying to make a comparison with respect to a child whose identity is not the same in the two scenarios.

Thus, there seems to be no way for either option to be better or worse *for* a particular child since the alternative for each possible child is non-existence; it is, after all, a different-child choice. Given that Alice's life with her medical condition will be worth living and better than non-existence, it would be better *for her* if her prospective parents do not select against her condition. But, it would be better *for Alex* if his prospective parents do select against the condition Alice would have but he would not. Viewed from this perspective, it seems that, faced with a different-child choice, these prospective parents cannot help but do what is better for one possible child but worse for the other, whether they select or not.

The above take on different-child choices illustrates the so-called "non-identity problem."[56] The non-identity problem is a paradox about how we ought to consider the effects of our actions on future generations given that different possible courses of action

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[56] Chapter 16 of Derek Parfit's *Reasons and Persons* sparked the vast literature on the non-identity problem.

would result in different individuals being created in those future generations. How could it be that actions we take today could be morally right or wrong on the basis of how those actions will affect people in the future when those very actions we take today will affect which people will exist in the future? How can we act out of consideration of the interests of future persons if some, but not all, of those potential future persons' interests would be best served by each alternative action available to us? If, for example, a future person will not exist if we do not pollute the environment because that person's parents will only meet and procreate as a result of migrating away from a polluted region, then how could our polluting be a moral wrong against her? She will only exist if we continue to pollute, so any explanation of the wrongness of polluting cannot include its ill effects on her. She owes her life and its goods to our polluting, so she does not seem to have the standing to object that our polluting wronged her even it does impact her environment negatively. Assuming that her life, on balance, includes more good than bad, she does not seem to be in the position of having been wronged by our actions. In fact, she seems to have benefitted from our polluting, since she would never have existed otherwise.

In the context of different-child choices and reproductive selection, how could creating a child knowing she will have a serious medical condition (albeit one that is compatible with a life worth living) be bad or worse for that child when the only alternative for her is to never come into existence at all? If it is not possible for us to create her without the serious medical condition, then creating her with the serious medical condition must be better *for her* than not creating her at all. Thus, because of the non-identity of the different possible and actual children in the different-child choice, it seems there is no way in which any actual child who is created is, herself, worse off, whether prospective parents select or not. If a child affected by the serious medical condition that is compatible with a life worth living is born, this cannot be worse for her since the alternative is non-existence and, by hypothesis, her existence is worthwhile and better than non-existence.[57]

The non-identity problem suggests the prospective parents do not seem to wrong any particular child no matter what they decide to do in a different-child choice. If they select against the medical condition and create a child like Alex, they have benefitted him without wronging Alice, who simply will not exist and therefore cannot be wronged. And, if they decide not to select and create Alice, they have benefitted her without wronging Alex, who will not exist and therefore cannot be wronged. Whichever course they choose, these prospective parents benefit the child they create without wronging anyone, including the merely possible children they choose not to create. Thus, the non-identity problem approach to the ethics of reproductive selection in different-child choices seems to conclude that selection in itself is morally neutral since no one is wronged in the process.

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[57] As stated in the previous footnote, the literature on the non-identity problem and even on the non-identity problem with respect to reproduction is vast. See, for example, Dan W. Brock, “The Non-identity Problem and Genetic Harm: The Case of Wrongful Handicaps,” *Bioethics* 9.2 (1995), 269–276; David DeGrazia, *Human Identity and Bioethics* (New York: Cambridge University Press, 2005); Jonathan Glover, “Future People, Disability, and Screening,” 429–444; Ronald Green, “Parental Autonomy and the Obligation Not to Harm One’s Child Genetically,” *Journal of Law, Medicine, & Ethics* 25 (1997), 5–15; Matthew Hanser, “Harming Future People,” *Philosophy & Public Affairs*, 19.1 (1990), 47–70; Caspar Hare, “Voices from Another World: Must We Respect the Interests of People Who Do Not and Will Never Exist?” *Ethics* 117. 3 (2007), 498–523; David Heyd *Genethics* (Berkeley: University of California Press, 1992); Jeff McMahan, “Causing Disabled People to Exist and Causing People to Be Disabled,” 77–99; Josh Parsons, “Why the Handicapped Child Case Is Hard,” *Philosophical Studies* 112.2 (2003), 147–162; J. David Velleman, “Persons in Prospect,” *Philosophy and Public Affairs* 36.3 (2008), 221–288; David Wasserman, “Ethical Constraints on Allowing or Causing the Existence of People with Disabilities,” in *Disability and Disadvantage*, ed. Kimberlee Brownlee and Adam Cureton (Oxford: Oxford University Press, 2009, 319–351; and David Wasserman, “Hare on De Dicto Betterness and Prospective Parents,” *Ethics* 118.3 (2008), 529–535.

4.2 Reply to the Non-identity Problem: A Different Sense of Children being Better or Worse Off

Those who worry about the non-identity problem notice that different actions can result in different people being created, and from that observation they conclude that such future people cannot be better or worse off in one scenario than another because they only exist in one scenario or another. There cannot be a comparison of the circumstances relative to a particular person who only exists in one possible future but not the other. But, these considerations, while interesting, are not at the core of what people are worrying about when they wonder about the ethics of selection in different-child choices. There must be a different sense in which the child born as a result of a different-child choice is "better off" and "worse off" than the sense that generates the non-identity problem. This different sense of "better off" and "worse off" ought to be able to capture the comparison we struggle to make when comparing the prospects of one possible child with a serious medical condition with the prospects of a possible child without that condition. To show this, allow me to return to Alice, the child who can only be created with a serious medical condition.

Imagine that Alice's parents choose not to select against the medical condition they know they are at risk of passing along and create Alice. Once she has grown up enough to understand the context that led to her creation, it seems reasonable that Alice could believe that it would have been better for their child if her parents had selected against the condition she inherited. She knows that such a selection procedure would have prevented her from being created in favor of a different child that they would have had instead. So, she understands that it would not have been better *for her*, since in this hypothetical scenario she would not have been the child her parents would have created. But, Alice believes it would have been better, in a different and important sense, for their child to have been born without the condition she has. She does realize that her creation was a different-child choice and that the child who would benefit from being better off would not be her. And, she judges that it would have been better, in a sense, for their child if her parents had selected against the relevant condition.

So, what is going on here? Is Alice wishing that the impossible could be possible? The does not seem reasonable. Is she wishing that she had never been created? That seems implausibly selfless. It seems to me that we can understand Alice as reasonably wishing that she could be the kind of person who is born without the genetic profile that corresponds to her condition. This wish seems problematic when phrased in the language of the non-identity problem; Alice does seem to be wishing, futilely, that the impossible be possible. In one sense—the sense that generates the non-identity problem—that is exactly what she is doing. But, she can also be understood as lamenting her situation and wishing that she could have had fewer challenges when she was born. She could be understood as expressing the judgment that her initial situation in life would have been better without her medical condition, apart from any limitations on which individuals could have such an initial situation, given current reproductive technology.

Notice that most prospective parents have similar wishes for their children to be born healthy, free from serious medical conditions. There is no metaphysical mystery generated by prospective parents wishing that their children, whoever they will be, will have greater opportunities and fewer challenges. The wish only seems puzzling in regard to individuals whose identity is tied up with a trait that creates burdens or disadvantages, as in different-child choices, because in different-child choices those individuals can only exist if they exist with the burdens or disadvantages. But, the recognition that an individual would have been better off without that burden or disadvantage makes sense when understood as an evaluation of the challenges she faces as a result of her initial situation. In effect, she wishes that her parents could have been in a same child choice instead of a different-child choice when they created her, while understanding that that was not the case. Alice wishes that there could have been a way to prevent her condition without necessitating that a different child be created instead of her. There is nothing implausibly selfless about this wish.

In fact, this wish is all too familiar to anyone who faces a different-child choice. Of course, it would avoid thorny metaphysical and ethical worries if we could create any particular child, whomever they will be, without the kinds of medical conditions that burden and disadvantage those who have them. No prospective parents who are motivated by doing what is best for their child reasonably want to be in the position of having to select one potential child instead of another. But, they do want to do what is best for their child, and there is a very real sense in which it makes sense to judge that it would be *better for* the child for her to be created without a serious medical condition contributing burdens and disadvantages to her initial situation.

In order to make it more clear how we can understand Alice's judgment as familiar and ordinary rather than metaphysically paradoxical, consider your own advantages and disadvantages that resulted from your traits and circumstances when you were born. We can all assess the quality of the initial situation with which we were created, whether or not we have a serious, congenital medical condition or any other potentially preventable trait, like being born into poverty, an abusive home, or many other disadvantaged circumstances. Different-child choices can be medical, environmental, or having to do with the readiness and fitness of potential parents. Even if it could not have been better *for me* to have been born into different circumstances because changing those circumstances would require my parents to create a different child, it is still possible to assess whether it would have been better *for the child*, whichever one she is, to born into her initial situation as opposed to for me to be born into mine. We can assess the prospective parents' different-child choice based, at least in part, on the implications for the resultant child's initial situation, whichever child that may be as a result of that decision.

Thus, even if we recognize the applicability of the non-identity problem to different-child choices, there is an important way that selecting to create one child with a certain trait instead of a different child without that trait can be good or bad for the actual child born in this situation. There is another sense in which is it bad for someone—anyone, no matter which particular individual it is—to be born with a disabling condition that her parents chose not to prevent even when preventing that condition would require that they create a different child. Similarly, it is better, in this other sense, for someone to be born without a disabling condition that her parents selected against. This important sense of it being better or worse for the children is a crucial consideration when evaluating the ethics of different-child choices in reproductive selection, and it cannot be overlooked in a full account. To the extent that recognition of the non-identity problem leads us to conclude that the resultant children cannot be better or worse off as a result of these choices, the non-identity problem can mislead us and cause us to overlook important considerations about the created children's interests. In the next section, I return these interests to the forefront of this discussion.

4.3 Reclaiming the Notions of Better Off and Worse Off: Evaluating the Advantages and Burdens of Different Initial Situations

In what sense is it better *for a child* not to have a burdensome or disadvantaging medical condition? Being born without such a condition contributes toward having a good start in life, a good initial situation. For any child who is created, it is better *for her* to have a wide range of opportunities and a manageable set of burdens at the offset. It is better for the child that she be born in a time and place of peace and prosperity rather than in the midst of a war, poverty, and/or famine. It is better for the child to grow up in a time and place in which effective, affordable medical care is readily available. And it is better for the child not to have a serious medical condition that is significantly burdensome. The opportunities and advantages she has at the outset increase the likelihood that she will be able to flourish and live a rich life, while the burdens and disadvantages she has as part of her initial situation increase the likelihood that she will suffer or struggle to overcome these obstacles to flourishing.

As Seana Shiffrin convincingly argues, creating a child not only benefits that child with all of the opportunities and goods of living that life but also imposes challenges and burdens that she must endure.[58] Creating a child is better understood as a "mixed blessing"[59] than as purely a gift, despite the widespread view of procreation as

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[58] Shiffrin, "Wrongful Life, Procreative Responsibility, and the Significance of Harm," 136–137.

[59] Ibid., 144.

granting the so-called "gift of life." Shiffrin's characterization of creating a child as a mixed blessing, an act that confers both positive and negative elements to the child, is helpful when thinking about the ways in which it is better or worse for a child to be created in the context of a different-child choice. If Shiffrin is correct—as I believe she is—that all procreation is at best a mixed blessing, then prospective parents ought to be aware that they run the risk of tipping the scales too far in the direction of burdens, challenges, and disadvantages. They ought to take reasonable measures to avoid inflicting an overly burdensome initial situation when they can. Shiffrin shows that all procreation imposes some burdens on the children created,[60] even in the absence of a serious medical condition or significant environmental hardship like famine, poverty, or warfare. Given that creating a child imposes a mix of goods for her to enjoy and burdens she must bear, it seems clear that we can compare the relative balance between goods and burdens for any particular initial situations and make judgments about which are better and worse for a child to face upon her creation.

Both a child born without any serious medical conditions and a child who is born with one can, and likely will, compare their situations to others'. The child with the serious condition might well note that she is fortunate to have the advantages she has and that she is worse off than others who do not have the disadvantages she has. She can make these comparisons even if it is the case that the only way for a child in her position to have the advantages she lacks would be for a different child to occupy her position and

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[60] Shiffrin writes, "By being caused to exist as persons, children are forced to assume moral agency, to face various demanding and sometimes wrenching moral questions, and to discharge taxing moral duties. They must endure the fairly substantial amount of pain, suffering, difficulty, significant disappointment, distress, and significant loss that occur within the typical life. They must face and undergo the fear and harm of death. Finally, they must bear the results of imposed risks that their lives may go terribly wrong in a variety of ways" (ibid., 137).

for her herself never to have been born, i.e., even if the non-identity problem applies to her situation. The non-identity problem seems to imply that only once a child exists can she be made better or worse off by a chance in her circumstances. Only a loss of some advantage or good that a child once had can make a child worse off, according to this way of thinking, because her existence is stipulated to be better for her than nonexistence. But, a disadvantage or burden need not be a loss to a particular person for it to be "worse for" her to have it. The contrast is between the situation she (or anyone else) with that disadvantage faces and the situation anyone without it faces.

To see why this is, consider the burdens borne by two blind children, Ben and Carol. If Ben initially has good eyesight but goes blind due to an injury or infection after he is born, then his lack of eyesight is a loss to him. In his initial situation he had sight, but his condition worsened relative to that initial condition. And, after he loses his eyesight, he is clearly worse off. Carol's blindness, however, is congenital, and current testing and technology provide a way to prevent her form of blindness, say, but only by selecting to create a child who will not have it. Thus, the only way for *her* (and not some different child) to be created is with blindness, at least given current technology. If her blindness does, in fact, make her worse off in some way, it cannot be in the same way that Ben's does, since her blindness is not a worsening of her situation—it is not a loss to her—but rather a part of her initial situation.

But the fact that Ben's blindness is a loss but Carol's is not is consistent with the claim that it is not good for either one of them to be blind. Both would most likely be better off if they could see, in the sense that they would be burdened by the inability to see. Both Ben and Carol will face challenges in their everyday lives. They will require accommodations that will complicate their education and careers. They will depend on assistance from others in ways that their sighted peers will not. Of course, these added challenges are not necessarily insurmountable, and Carol and Ben might flourish and succeed in spite of, or even because of, their experiences as blind individuals. But, whether congenital or a loss suffered at a later point, the challenges face by those who have serious medical conditions such as blindness are burdens or disadvantages that make their lives more difficult.

We can recognize that having a disabling condition or other kind of disadvantage is not necessarily a loss and still hold that it is a burden that imposes challenges and is in that sense bad for the person who has it. Sometimes challenges inspire greatness. But, in general, when it comes to creating children, minimizing challenges where possible and taking steps to provide the best opportunity for them to thrive is good for the children. (This is the lasting insight gleaned from accounts based on the notion of an obligation of parental beneficence.)

Thus, it seems to me, there is a clear, important sense in which a person who is born with a disabling condition whose parents refrained from selecting against it—that is, they chose not to select in order to create a different child who would not have had the condition—is worse off. She is not worse off than *she* could have been because of the non-identity problem. But, she is worse off than others who start off life with fewer challenges. Her initial situation is worse than others' initial situations. She would be better off if her initial situation had been better, just as she will be better off if we treat or manage her condition, after her birth. In this sense, the fact that she is worse off in terms of the balance of advantages and disadvantages in her initial situation is orthogonal to the fact that the only way, given current technology, to prevent her condition is by selecting to create a different child. It is true that *she* could not exist without her condition and so, for her, there are only the options of existing with the condition or not existing at all. But, it is also true that her initial situation is worse than other possible initial situations because of her condition. And, someone born into a worse initial situation is worse off than someone born into a better situation. Thus, there is an important sense in which selecting against a serious medical condition is better for the resultant child who will be created, whichever child that may be.

The different-child choice is a decision about creating one child with an initial situation that is known to include a significant disadvantage as opposed to creating another child without that known type of disadvantage. It is a choice between two types of initial situations, or between the presence and absence of a particular genetic trait. It is not a choice between two known persons that requires a judgment about which person is more valuable or worthy of being created, as I argued above in Chapter 2. Two initial situations can be meaningfully compared in terms of the advantages and disadvantages they have without requiring knowledge about the identity of the individuals who will be created into them, so the initial situations can be meaningfully compared despite the non-identity of the children who would be created into them.

As I showed in Chapters 2 and 3, those comparisons involve many variables, and there are significant problems with trying to compare the relative advantages and disadvantages across all of those variables. But, often in reproductive different-child choices the only available information is about the presence of absence of one particular genetic trait (or possibly a few), so the comparisons are simplified, at least in terms of the number of variables. The difficulties discussed in Chapter 2 about the sensitivity of judgments about the value of having these traits certainly calls for care. But, the fact remains that we can assess the burdens imposed by heritable conditions from Tay-Sachs disease to cystic fibrosis to deafness to attached earlobes. We can meaningfully compare the initial situation of having one of those conditions with initial situations that lack these conditions. With respect to these four examples, it seems clear that the first three impose significant burdens, perhaps in decreasing degrees of severity, while the last one, having attached earlobes, does not seem to impose any burdens. If prospective parents can find out through testing that one embryo has a genetic mutation consistent with cystic fibrosis, for example, and another does not, then they can meaningfully compare the known burdens of these two genetic profiles and judge that the initial situation of having cystic fibrosis is worse than the initial situation of not having it.

These comparisons and judgments about which initial situation is better and which worse can be made without bringing along any value judgments of the worth of the particular child who would be born into it, in accord with the requirement of respecting the equal worth of persons with disabilities and serious medical conditions that I affirmed in Chapter 2. Preferring and, all other things being equal, even selecting a less burdensome initial situation does not necessarily express any value judgment about any people or groups of people. Rather, that preference expresses a value judgment about whether having a certain medical condition contributes to a better or worse initial situation.

Thinking about better and worse situations for children to be born into can be understood as analogous to thinking about better and worse environments for children to live and learn in. Building a house or a school with safer, more expensive materials and construction methods will create a better environment for the children who will live or go to school there, which is better for the children in the sense of "better off" or "better for" that I have argued applies to selection. Using those safer materials and construction methods is better for the children even if it means that different children will be in that environment due to the higher property values or tax levels. The fact that one set of children will enjoy the higher quality housing and schools if we select the safer, more expensive building projects while a different set of children would live and learn in those buildings if we select the less expensive options does not factor into our calculations of which option is better for the children, whichever children they will be.

4.4 What We Learn from the Non-identity Problem

There is a metaphysical oddity in thinking about how decisions about what action to take now we ought to take in order to avoid making things worse for future people when those very decisions determine which future people will exist and which will never be created. With this oddity in mind, it seems impossible that different-child choices in reproductive selection could make any child better or worse off since the very choice itself determines which child will be created and which will remain nonexistent, merely possible children. The fact that it seems impossible to affect a particular child's interests either positively or negatively by choosing to select her or not seems to imply that the child's condition cannot be a morally relevant factor in the decision-making process, since, even with a serious medical condition, as long as that condition is compatible with a life worth living, the comparison will always come out in favor of creation rather than nonexistence.

But, we can make sense of selection as affecting the resultant children's interests in ways that are better or worse, despite worries about non-identity. Being born with or without a serious medical condition has a significant impact on the balance of advantages and disadvantages a child faces. While disadvantages in no way decrease the value of a person and do not necessarily preclude the possibility of flourishing, they do burden and challenge the child created with them. As prospective parents who want to do what is best for their children, those who must make a different-child choice must consider those burdens as relevant moral considerations. Thus, those children's interests in having fewer challenges as part of their initial situation can count in favor of selecting against serious medical conditions.

This way in which having a serious medical condition can be worse for a child explains why selection against Tay-Sachs disease is required when prospective parents are at a significant, known risk, but selection is controversial for conditions like deafness. The burdens suffered by an infant with Tay-Sachs disease bring her quality of life below an acceptable minimum, and that suffering should therefore be prevented where possible. With respect to deafness and many other conditions that are less severe than devastating conditions like Tay-Sachs disease, the decision about whether to select or not should take into consideration the disadvantages the child will face, but those disadvantages are unlikely to be decisive. Depending on the child's culture, social institutions, and family resources, those disadvantages will vary significantly in number and in degree. As I argued in Chapter 4, the suggestion that there is a parental obligation to maximize goods in their children's initial situations is implausibly strong, but there is moral reason for prospective parents to do what they reasonably can to give their children a good chance at a rich, fulfilling life. Knowingly selecting to create a child with a significant disadvantage instead of one without that specific disadvantage seems directly counter to the goal of giving a child a good chance at a rich, fulfilling life. What the child does with that chance, we cannot, of course, completely control, nor should we try to, on pain of failure to demonstrate acceptance.

As with the other approaches discussed in earlier chapters, the non-identity problem does not give the full story when it comes to the ethics of reproductive selection in different-child choices. If anything, it distracts attention from a different—and very important—way in which having a serious medical condition can be worse for a child than not having that condition. This sense of being better or worse off is certainly relevant to the ethics of reproductive different-child choices. Thus, to the extent that recognition of the non-identity problem seems to entail that selection is morally neutral, paying too much attention to the non-identity problem leads us astray.

PART III: ASSESSING THE EXISTING APPROACHES AND A NEW APPROACH

Chapter 5

Returning the Focus to the Parental Aim of Doing What is Best for Their Child

5.1 Taking Stock: A Summary of the Lessons Learned from the Existing Approaches

Prima facie, the existing approaches discussed above characterize an act of selection variously as an expression of a moral failing or character flaw, the fulfillment of a parental duty, or an illustration of a metaphysical paradox. Prospective parents with prejudiced views about people with disabilities and medical conditions could use selection as a means to express those morally problematic views. Selection could also be a way to demonstrate a failure to be accepting of children who do not meet some standard that prospective parents make a prerequisite for joining their family. In these two ways, an act of selection is a moral wrong if it is done from these sorts of morally objectionable motives. Or, an act of selection could be a morally required action if it is performed in order to fulfill a parental duty to give one's children a good chance at a good life, for example, by preventing a devastating condition like Tay-Sachs disease. Finally, a different-child choice illustrates the paradox of the non-identity problem, since it is a situation in which there is no one particular child who is better off, whatever the prospective parents choose. In different-child choices, the identity of the child is not fixed, so there is a puzzle about how to make sense of the seemingly better and worse conditions of *the* child when the child the prospective parents would create if they choose one course of action is not identical to the child created if they choose the other course of action. Whether prospective parents choose to select or to refrain from actively selecting, the non-identity problem suggests that the result will be better for one (or more) child but at the same time worse for others.

Taken together, then, these existing approaches seem to suggest that prospective parents who must make a different-child choice have no good option. In one of their first parental decisions, there seems to be no way for them to do something good for their child. If they select, then they fail to be accepting, as good parents ought to be, or they express derogatory attitudes toward existing people with the trait they select against, or both. If they refrain from selecting and leave their procreation to chance, then they fail to promote their child's well-being by providing the best chance at the best life for their child. Either way, they necessarily fail to satisfy an obligation; they seem to fail to be good parents before their child is even born. They might also fail others by insulting and harming them. But, whatever they do, it cannot be better or worse for their child, according to the non-identity problem. So, even though our prospective parents started off by trying to do what is best for their child, they neither can achieve that goal nor can they avoid further failings, or so say these existing approaches when taken together, at face value.

As I argued in Chapters 2–4, however, upon closer examination, the intuitions behind each of the existing approaches can be developed in order to yield more plausible—and consistent—insights. From the expressive effects worry, we learn that there is a need for care and compassion when making decisions that sometimes are expressive of a hurtful, damaging, derogatory message to people who are already harmed by such attitudes. Prospective parents—and all of us—ought to be aware of the reality of the burdens and disadvantages imposed by a particular condition before acting on any unfounded assumptions. With a better understanding of both the physical burdens imposed by particular conditions themselves and the disadvantages people with those conditions face as a result of prejudice or social factors, prospective parents can guard against complicity with objectionable norms and more accurately evaluate the impact that having a particular condition will likely have on their child's life.

Ultimately, however, while selection *does* include, and therefore express, a value judgment about the contribution of a particular genetic trait or medical condition to one's well-being or their likelihood to thrive, it does *not* necessarily express any sort of negative value judgment about the value of the people who have those traits and conditions. Thus, prospective parents who are making a different-child choice should determine if they are considering selection out of prejudice or morally objectionable views about the worth of people with disabilities and medical conditions. If so, then they should reconsider and revise those views. Selection on that basis is morally objectionable. But, if the prospective parents are considering selection out of legitimate concern for the impact the genetic trait would have for their child's well-being, then they should, first, determine if their concern is well-founded by researching the impact of having that trait on a person's prospects for living a good life and, second, look beyond the expressive effects worry for an answer to the question of whether they ought to select in their own specific circumstances.

In addition to the expressive effects caution against selection, the approach that emphasizes the importance of acceptance in good parenting also cautions against certain types of morally problematic selection. Prospective parents are in danger of failing to be good parents if they decide to select out of a lack of acceptance when the traits they seek to avoid are traits that they should not discriminate against. Prospective parents ought to accept their children for who they are, not organize their family like an exclusive club that requires its members to have only certain desired features. Thus, prospective parents who are making a different-child choice should determine if they are considering selection out of a lack of sufficient acceptance of their children, since they should not select on that basis.

To try to make use of selection as a tool for narrowly controlling which types of children are allowed into the family is morally wrong, but, the obligation to love one's children in an accepting way is not an absolute obligation. It must be balanced with other, sometimes conflicting obligations, including the obligation to nurture and encourage development in your kids. Thus, selection is not necessarily a failure of the acceptance requirement. The caution about approaching parenthood with a sense of acceptance is best understood as a caution that selection undertaken from a motive that is not accepting is morally wrong. But this caution is not the final word about the morality of selection. If prospective parents who are making a different-child choice determine that their motives for considering selection are neither derogatory nor insufficiently accepting, then they still need to look beyond the expressive effects worry and the parental acceptance requirement for an answer to the question of whether they ought to select.

While the expressive effects and parental acceptance approaches warn against the prospect of wrongful selection, advocates of the principle of parental beneficence encourage, or even require, selection as a way to fulfill a different parental obligation. They urge prospective parents to aim to give their children the best shot they can at a good life. But, this requirement on parents cannot plausibly be as strong as an absolute requirement to create only children who have the best chance at living the best possible life among all of the possible children they could have. Not all prospective parents must make use of all available screening, testing, and assisted reproductive technologies to ensure that they create only the best possible children they can; not all prospective parents have reason to make a different-child choice.[61] Only when prospective parents know, ought to know, or have good reason to suspect that they are at significant risk of passing along a serious medical condition to their offspring do they face a different-child choice.

For prospective parents with no family history of serious, heritable conditions; no reason to suspect consanguinity; and no membership in ethic groups at known elevated risk for specific conditions, there is no requirement for them to make use of testing and assisted reproductive technologies in order to select only the "best." Absent any good reason to believe that their children are at significant risk of inheriting a serious medical condition, prospective parents can permissibly conceive their children naturally, without any selective intervention. As noted above, competing obligations must be balanced, and parental beneficence is not the only consideration that is salient. Like the acceptance requirement, a parental beneficence requirement must be understood as one of multiple considerations that might conflict but that help delineate the boundaries on permissible procreating. Creating a child in a loving, stable environment with a reasonable

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[61] I thank Barbara Herman for encouraging me to take up this point.

expectation of a mix of benefits and burdens within the normal range for that time and place is enough to satisfy this requirement. There is no requirement that parents do everything they possibly can to maximize their children’s prospects, which means that not all prospective parents must make use of assisted reproductive technologies to create only those children who have the best chance at the best life.

The requirement of parental beneficence is, in its most plausible form, a requirement that prohibits recklessly creating children who will bear hefty burdens when the parents know that there is a significant risk and are in a position to prevent those burdens using means that are not themselves objectionable. Which conditions impose sufficiently hefty burdens for this requirement to apply is a difficult question. Tay-Sachs disease and other similarly devastating conditions most clearly fit this description. But, it seems to me that less severe conditions do as well if they cannot or will not be adequately treated, managed, or accommodated so as to allow those who have them to have a good chance at living a good life. Creating a child with a serious medical condition is only reckless if (a) the parents know that they are at risk or are in a situation in which it is reasonable to expect them to know that they are at risk and if (b) the condition cannot or will not be treated, managed, and/or accommodated so as to provide their child with a good chance to live a good life.

The requirement of parental beneficence is also an imperative that prospective parents take reasonable steps to be aware of any elevated risk of serious medical conditions their offspring face and to take those risks into consideration before procreating or procreating without selective interventions. Hoping for the best or leaving their child’s traits to chance, a higher power, or nature might have been the best that past generations of prospective parents at risk of passing along a serious condition could do. But, with advances in screening, testing, and assisted reproductive technologies now available, at least to some, hoping for the best is no longer enough. Prospective parents who have no access to the information that they are at significant risk or who have been misinformed about relevant facts such as their parentage, ethnicity, or family medical history through no fault of their own are not reckless when they do not act on this information that they cannot be reasonably expected to have. Only now that such relevant information is available through advances in genetics are prospective parents required to take reasonable measures to seek out that information and, in some cases, select on its basis. Previous generations and those who do not have access to genetic testing or assisted reproductive technologies do no wrong when they do not select. That option was not or is not available to them. But for those to whom it is available and who can be reasonably expected to know that it is morally salient to their procreative decision making, selection is required when the condition is severe enough and the prospects for treating, managing, or accommodating it are insufficient to provide a good chance at a good life.

Prospective parents must take reasonable measures to provide their children with a good chance at a good life, and that means preventing, treating, managing, or accommodating conditions that interfere with having a good chance at flourishing when they can reasonably be expected to know that there is a risk of a child having such a condition. It is for these reasons that we try to protect children from illness and injury and to provide them with opportunities to develop their capabilities. These are also the reasons that parents who know or ought to know that they are at risk of passing on a serious medical condition have an obligation to try to prevent or mitigate the effects of that condition, by selection or other measures. But, if there is no reasonable way that prospective parents could have known ahead of time that their children were at risk of inheriting a condition, no matter how severe or if there was nothing they could do to prevent it, then there is no moral failing on the part of those parents if they create an affected child. They will have obligations to treat, manage, and accommodate the condition going forward, but they did nothing wrong in creating the child since there was no reasonable way for them to have known about the risk.

Finally, after considering the non-identity problem and the relevant ways in which creation can and cannot be better or worse for the individual created, I concluded that selection (and refraining from selection) *can* be better or worse for the children who are created, in an important sense of "better" and "worse." Their initial situations are evaluable as better or worse in terms of the balance of advantages and disadvantages a newly created child faces. It is better for a child to have a manageable set of challenges when she is starting off life than to be burdened with an overly heavy load of disadvantages. And, given that parents ought to do what they reasonably can to give their children the opportunities and resources to have a good chance at a good life, it seems clear that selection is required in some cases in which prospective parents are at a known, significant risk of passing on a serious medical condition to their children.

In summary, it is morally wrong for prospective parents to select against a genetic trait out of a prejudiced attitude toward people with disabilities and medical conditions. It is also wrong for prospective parents to select out of a motive that is insufficiently accepting. But, in cases in which a child's creation would impose burdens on the child that are too great and cannot or will not be treated, managed, or accommodated so as to provide her with a good chance at living a good life, it is morally wrong for prospective parents to create such a child. In these cases, prospective parents ought to select against those conditions if they want to create a biological child of their own. In addition to these categories of selection that are impermissible because the prospective parents' motives are objectionable and required because procreating without selective intervention would be reckless, respectively, there is a range of cases in which selection is permissible. In these cases, the question of whether prospective parents should select depends to a large degree on how good or bad the child's initial situation would be and how well the burdens the child would bear can be mitigated. For the remainder of this dissertation, my focus will be on the cases of different-child choices for which selection is permissible and the question of how prospective parents ought to decide whether to select in these kinds of cases.

5.2 Why the Existing Approaches Cannot Capture the Full Story

There is something worthwhile in each of the existing approaches discussed above, at least when they are presented in their most compelling forms. But, there is more to the moral landscape that requires attention in order to make progress toward a complete account of the ethics of reproductive selection. The four existing approaches above, each in its own way, encourage us to think about different-child choices primarily from the perspective of the interests of people other than the children being created. But, I will argue, only an approach that recognizes the importance and centrality of the children's interests can capture the full complexity of the ethics of reproductive selection in different-child choices. In this section, I begin by describing how each of the existing approaches tends to focus elsewhere, and then I offer an argument for why these approaches cannot succeed in capturing the full story without adequate attention to the children's interests.

If, as those who focus on the expressive effects worry suggest, the main moral problem with selection is that it expresses a derogatory attitude toward people who have the trait others aim to select against, then selection is impermissible because of the moral impermissibility of having and acting on a derogatory attitude and because of the harm it does to existing people who have that trait, where it does such harm. The prospective parents who select, according to this view, commit a moral wrong, and that act is wrong because it demonstrates a character flaw and because of the harm it does to third parties. By focusing on the derogatory or discriminatory attitude expressed in some acts of selection, this approach focuses on the moral character of the selectors and the moral effects on existing people who have the relevant trait as well as society as a whole, but this approach is silent on the interests of future potential children, except insofar as the derogatory attitudes would impact them in the future if they came into existence. The expressive effects approach considers only the attitudes and values expressed by the act of selecting and the effects on existing people, not about any other kinds of implications for the child and her interests. This approach tends to cut off discussion about the possibility that selection might be permissible without even considering the implications for the child of being born with the relevant condition or without it in contexts when prospective parents must make a deliberate decision to create a child who most likely will have the condition or who most likely will not have it.

Like the expressive effects worry, approaches that focus on parental obligations run the risk of implying that the morality of selection is more about the prospective parents and their character than about the children's interests. In the approaches based on each of the two conflicting parental obligations above, the focus is on the question of what is required for a person to be a good parent and what character failings they have if they do not demonstrate adequate beneficence or acceptance. Accounts based on a principle of parental beneficence note that parents ought to do what they can to give their children a good chance at a good life, and from that conclude that selection must be pursued where it promotes that principle. Assessing whether or not selection promotes parental beneficence, of course, requires calculations about which genetic traits correspond to the best chances at the best life. For this reason, the parental beneficence approach devotes more attention to the child's interests than the others, though I maintain that the approach's primary focus is on determining which option would best display a desired trait in the parents rather than on determining which option would be best for the created child, whichever child that is. Accounts based on the obligation to accept children as they are counter that selection violates that obligation and therefore must not be pursued. But, this focus on the parents and what their views about selection reveal about their character—whether they reveal bigotry, a lack of beneficence, or insufficient acceptance—can only tell part of the story. To be sure, parental virtues and vices are relevant to the question of the ethics of selection, but so are the child's interests. Cutting off the discussion before the child's interests are fully considered leaves out the central player's interests.

The non-identity approach is the most extreme in its discounting of the child's interests. Concern with the non-identity problem leads to an approach that not only underemphasizes the created child's interests, whichever child is created, but goes so far as to claim that no particular child's interests are even relevant to the moral question of whether to select or not. Here, the problem is not oversight or underemphasis but a denial of the fact that the child's interests are morally salient. According to the non-identity approach, it is metaphysically impossible that there can be a determinate subject to be affected by selection, since, given current technology, the determinate offspring who will come into existence if we refrain from selecting are not identical to those who will come into existence if we do. They will be different children, so their only relevant interests are those related to the goods and bads of existence. It cannot be better or worse for them if we select except insofar as it is better or worse for them to exist or not. So, on this approach, it seems to be nonsense to worry about the interests of any particular prospective child. Thus, the paradox of the non-identity problem implies that the morality of selection must be determined by something other than the particular child's interests. Not only does this approach fail to include the child's interests from consideration, it argues that the child's interests cannot be morally relevant to the decision.

Why is it a problem that these existing approaches focus on interested parties other than the child? Why not just think about and try to balance considerations about how hard it would be for the parents, what it would cost society, and how it would hurt existing people with these conditions in order to explain why selection is permissible or impermissible when it is? For one thing, looking to the various burdens borne by the family and the community or the objectionable attitudes that may find expression in selection in order to judge the morality of selection is like trying to settle the question of what is wrong with stabbing a person in terms of the damage done to her clothing.[62] While the blood stains and cuts through the fabric do presumably contribute a little bit to the harm done to the stabbing victim, they are incidental when compared with the damage to her body and psyche. So, too, it seems admittedly relevant if taxpayers will be expected to contribute revenue to provide services and accommodations for children born with serious medical conditions, but the burden on taxpayers is incidental when compared with the burden borne by the child herself. Whether an argument seeks to defend or condemn the practice of selection in a particular case, the child who would be created as a result of selecting or refraining from selecting has interests that are more germane than those of her fellow citizens, siblings, and even her parents.

In addition, an overemphasis on the parents' interests contributes to a troubling and naïve view about the reality of how much control prospective parents have over procreation. Creating a child—or even trying to create a child—opens up prospective parents to all kinds of unexpected and unknown burdens. Of course, it opens them up to unexpected and unknown joys, too. But, to the extent that prospective parents believe they are controlling who their child will be by selecting against one or even several traits, they overestimate their capacity to control their child's identity, understood in a rich sense. (They also overstep the bounds of how much parents should want to control their child. Their child is, after all, becoming her own person, not just an extension of her parents.) Those who worry about the prospect of parents controlling their children, or creating "designer babies," make a similar overestimation. No matter how many genetic traits prospective parents determine, they can never determine the entirety of the person.

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[62] I thank Tiffany Cvrkel for suggesting this analogy to me.

No finite list of traits—genetic or otherwise—can capture the full richness of any particular person who will have those traits. There is simply too much room for diversity and variation even among individuals who share the same selected traits due to environmental influences, variation in the expression of genes, and other factors that are well beyond parents' control. Even identical twins, for all of their shared genetic traits, are different people with unpredictably different personalities, preferences, and values.

Even if parents could control the entire genotype, genotype is not destiny, and the expression of the selected genes could vary significantly. The kind of person their child might grow up to be and the traits she will have depend, in large part, on factors beyond any parent's control. In creating a child, parents create an individual who, if all goes well, is on a path to becoming her own person with her own preferences, values, ambitions, and vulnerabilities. While the parents may have some measure of control over the beginning of that path, their control is far from total, and it only decreases after the child is born and matures. Even if prospective parents could "design" a child by selecting a long list genetic traits from a menu of options, once the child is created, she and her environment contribute more and more to how those genetic traits are expressed, while the parents' control over the result diminishes over time as the other influences contribute and compound their effects. So, to think that the activity of selecting for or against one or even several genetic traits amounts to parents controlling their children's identities is a gross overstatement.

Ultimately, even a thorough, accurate account of the morally significant ways that selection affects prospective parents; other family members and loved ones; the community; society and its resources and institutions; and existing people with the relevant condition cannot settle the question of what those prospective parents, in their specific different-child choice situation in which selection is permissible but not required, should do. Presumably all of those admittedly relevant and admittedly morally significant considerations ought to contribute something to their deliberations, but the net balance of those costs and benefits to all of those parties is not going to settle the question of what they should do. Sometimes the course of action that would be more costly to these affected parties in aggregate is not the right thing to do, but sometimes it is. Any bottom line assessment of costs and benefits to everyone involved is not going to settle the question of what the best thing to do is for their child. The prospective parents are—or, at least, should be—focusing on how to do what is best for their child or children, first and foremost. The other considerations about the impact of their choice on others, while relevant, are not of primary importance and cannot settle the question on their own. The child's interests must play a prominent role in the decision-making process for the decision to be made well.

5.3 Returning the Focus to the Aim of Doing What is Best for the Child

Focusing on worries about the non-identity problem, the expressive effects of selection, and the tension between competing parental obligations takes the discussion about the ethics of reproductive selection a long way away from the initial goal of trying to determine how prospective parents ought to decide what is best for their children in a different-child choice. The metaphysical, social, and theoretical worries here are fascinating and have generated a sophisticated philosophical literature, but all of the ink spilled on these puzzles do not help Bonnie and Dan Rough—and many others facing different-child choices—to decide whether to select. Because the prospective parents are the ones who must make a decision, it is natural to focus on them and their interests. But, much of the existing literature about the ethics of reproductive selection focuses on the prospective parents' moral character, their interests, their family's interests, and the interests of third parties, including other people who have the relevant traits and the community more broadly, without paying enough attention to the interests of the children who are created out of these situations.

The main moral question that prospective parents who face different-child choices must grapple with is not how to solve the non-identity problem. It is not the question of how to ban the practice of selection because it is derogatory. The fundamental question is also not about how to quantify the odds of a person with a certain genotype living a good life, nor is it about what course of action would be most accepting. Rather, the central question is closer to the question our prospective parents started with in Chapter 1. How can they do what is best for their child when faced with a different-child choice? This question remains unanswered despite all of the debate about the ethics of reproductive selection discussed above.

No single consideration can settle the moral questions raised by selection because selection is a messy, complex category of activities. The morality of selection in a particular case depends on the genetic trait or condition in question, its severity, the way people with that condition are treated in the relevant society, the prospective parents' attitudes toward that condition and toward people with disabilities and serious medical conditions generally, and the prospective parents' resources, among other things. Selection is not morally bad, in the cases in which it is, because of a moral problem with selection itself. Not all cases of selection are morally objectionable. Selection is morally wrong, in the cases in which it is, when it is done for objectionable reasons, using objectionable means, or without due regard for important moral considerations. But, the same is true of speaking, running, and countless other types of action that are not inherently morally wrong but can be a central part of a derogatory, hurtful outburst or a shirking of an important duty to help someone in need, for example.

Selection is required, in the cases in which it is, when it prevents a child from being created with an overabundance of burdens when the risk of those great burdens is known and they can be prevented by means of selection. Drawing a line that between an acceptable level of burdens and an overabundance is a hard task. It seems to me that Tay-Sachs disease and any other condition that is not compatible with a life worth living is clearly on the overabundance side of the line, while inheriting two copies of a mutation that makes taste buds more sensitive to bitter tastes and thereby tends to make those who inherit them pickier eaters[63] seems to me to be clearly on the acceptable burden side of the line.

The hard cases for prospective parents to decide lie in the grey area between these extremes, where selection is permissible but not required. How should prospective parents in these cases figure out which option is best for their child? How should they think about what traits correspond to the best available initial situation? If they were making a choice about health care on behalf of some other close loved one, they would do well to refer to that person's personal values and preferences for guidance about what

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[63] Razib Khan, "Which Grandparent Are You Most Related To?" *Slate*, October 18, 2013, http://www.slate.com/articles/health_and_science/human_genome/2013/10/analyze_your_child_s_dna_which_grandparents_are_most_genetically_related.html.

would be best for that particular person in this particular situation. But, prospective parents do not know any of the particular values and preferences of any of those individual possible children. They *cannot* know those values and preferences for any individual possible child because those values and preferences do not yet exist. So, how should the prospective parents make decisions on their behalf, given this lack of information about, or even content in, the child's individual values, preferences, dreams, goals, and priorities? I take up this question in the next chapter.

Chapter 6

The Ethics of Reproductive Selection in Different-child Choices: Context-Dependent Proxy Decision Making

6.1 Deciding for a Loved One Whose Values Have Not Yet Been Established

Imagine some thoughtful, well-informed, and well-intentioned prospective parents who face a different-child choice. They will be accepting of their children, whatever traits they will have. They do not have negative or discriminatory attitudes and judgments about existing people with disabilities and other medical conditions. They recognize that they have some obligation to give their children a good chance at flourishing but no obligation to optimize their children's initial situation. And, they are aware of the non-identity problem but believe that a child can be better or worse off due to the balance of advantages and disadvantages, or benefits and burdens, in her initial situation. How should these prospective parents make their different-child choice? The preceding chapters give them a number of considerations to include in their deliberations, but we do not yet have the whole moral field in view.

These prospective parents still need a way to think about the concern that I suggested was foremost on their mind when I first introduced the problem of the different-child choice in the context of selection by means of assisted reproductive technologies: how to determine what is best for their child. The goal of doing what is best for their child (or children) requires an understanding of what is better and worse for the child who would be created. As I argued in Chapter 4, the question of what is better and worse for a child who has not yet been created is best understood as a question about evaluating the balance of advantages and burdens imposed on some child in the various possible initial situations available to a particular set of prospective parents. Determining what is better or worse for the child is further complicated by the fact that the child's individual values, preferences, and interests are not—and cannot—be known at the time the decision must be made. As I will argue in this chapter, prospective parents should approach their decision as proxy decision makers who rely on what information is available about the child's likely values, preferences, and interests but who also must rely on their best judgment as a loved one who cares for the future child and her well-being even before she is created, in the ways that such love and caring for someone is possible before she comes into existence and before her parents are acquainted with her personally.

Because the prospective parents are making their decision with concern for what is best for the child as their primary consideration, it resembles more ordinary, familiar cases of proxy decision making. What does more ordinary, familiar proxy decision making look like? Understanding how proxies can make good decisions in the simpler—though, admittedly, sometimes still very difficult—case of proxy decision making for an existing person ought to help shed light on how prospective parents can make similarly good decisions for their prospective children. To that end, I want to consider different types of proxy decision-making cases and what is required for good decision making in these situations before I return to the question of how prospective parents making different-child choices should make their decision.

Consider a case in which parents must make a health-care decision for an existing child or infant because she is uncontroversially too young—i.e., she has not yet developed the necessary decision-making abilities—to make the decision on her own behalf. This case, like the reproductive selection cases, involves parents making decisions on behalf of their children, but the case of the existing child is in some ways simpler because the child already exists, with a determinate identity and existing interests.

When parents of a small child or infant must make decisions about her health care on her behalf as her proxy decision makers, they ought to focus on what is best for their child. Just as I argued in Chapter 5, the fact that the parents themselves, other family members, and others in their community might bear costs as a result of their child's health needs might have some moral relevance, but those morally relevant costs are not likely to be the main considerations that will settle the question of what the parents ought to choose for their child. Their child's interests are of primary importance, while these other, admittedly salient, considerations tend to be of lesser importance. As proxy decision makers, these parents of an existing child are tasked with making decisions about her care from the perspective of what is best for her, and doing so requires including the child's interests in the deliberation as the primary consideration.

Of course, figuring out what the child's interests are might be a very difficult task indeed, not easily reducible to a question about expected levels of suffering, life expectancy, financial costs to the family, or any other singular measure. For example, a surgery might cause an infant greater overall physical discomfort than allowing a defect to go uncorrected, but if the surgical correction will allow her a wider range of social and developmental opportunities in the long term it might well be better overall for her to get the surgery. Or, in a different case, the physical discomforts of chemotherapy might not be better overall even if they will allow a small child some gains in life expectancy as well as in social and developmental opportunities. Balancing these and other relevant interests that the child has is no easy task.

Proxy decisions are best made in the context of a person's own preferences, interests, and values, whether that person is a child or an adult. What is best for one person in a certain situation is not necessarily best for a different person in a similar situation. How a health-care proxy decision ought to be made depends on the particular values, interests, and preferences of the patient. There are multiple reasonable ways to prioritize values and set goals for one's life, so there cannot be a one size fits all answer to many questions about health care that require resolving a conflict between competing values. The best ways to resolve that conflict will vary from person to person. For example, for an adult patient with a terminal condition who is dependent on life support, a proxy decision maker might have to decide whether to prioritize longevity or relief from discomfort. The answer to that question depends on the patient and her own priorities and personal values. For a patient who values quality of life or relief from discomfort over longevity, life support is unlikely to be the best option. But for a patient who prioritizes longevity and fighting to preserve life at all costs over relief from discomfort, life support makes a lot more sense. That is why the proxy decision maker, ideally, is someone who knows the patient well and can commit to make the decision as they believe the patient would make on her own behalf if she could.

Ideally, in proxy decisions, the person the proxy is deciding for has stable, known values and preferences that can guide the proxy in making a health-care decision on the patient's behalf. For example, imagine that a person with a terminal condition that does not impair his rationality has consistently expressed to his family members throughout his life, even before he got sick, that he does not want interventions such as feeding tubes and ventilators used on him at the end of his life. Knowing that the course of his illness is likely to include a slow decline and that the question will probably arise about whether to make use of these interventions, he has specific and frequent conversations with his loved ones explaining and reiterating his preferences. He selects his wife as his health-care proxy because he knows that she understands and supports his long-held preferences. She accepts his prioritizing of quality time with his family and friends without the presence of tubes and medical equipment limiting his ability to communicate over living the longest possible life he can. This man makes his wishes formal with legal documentation, and he arranges for a hospice provider to take over his care when his condition progresses to the point at which hospice care is appropriate. He has done everything he can to make his wishes clear, and his wife benefits from knowing what he wants. It makes her job as his proxy easier. His preferences have been stable, and he ensured that they were well-known to all of his loved ones. When the time comes, his wife declines the offer of a feeding tube and a ventilator. She makes these decisions on her husband's behalf in full confidence that she is acting as he would have wanted. Even as she grieves her own loss of a partner and struggles with the knowledge that his time was cut shorter than it otherwise might have been, her duty as a proxy decision maker was clear because the person she decided for had stable, known preferences and values.

But, that ideal of stable, known preferences is not always achieved in proxy decision-making cases. A person's values, preferences, and interests tend to change over the course of her life, sometimes in response to the very kinds of events or experiences that put someone in a position to need a proxy decision maker. Unlike the man described above with the stable, known preferences, many people do not think much about the kind of end-of-life care they prefer, including which specific interventions they are and are not comfortable with. For many people, decisions about health care and the preferences and values that inform those decisions get worked out on an as-needed basis, in response to developments in their medical condition that require a decision about whether to proceed with a course of treatment or not. Many people will never put much thought into the question of how much longevity and independence from medical equipment matter to them unless they have to because circumstances require them to choose between the two. Others might think they prefer one or the other but change their mind in response to the experience or circumstances of the conflict between the two. These are reasonable ways for people to manage their personal values and preferences, but the instability and uncertainty complicates the task of a proxy decision maker acting on their behalf.

How well the proxy knows the person's values and preferences and how they have changed, whether subtly or dramatically, over time can also complicate the proxy's task. In the ideal example of the man with stable, known preferences, he made a point of communicating his preferences and the priority of values that explained those preferences to his wife, other loved ones, and those in a professional capacity to act upon them. But not everyone covers all of these bases, even if they have thought about a conflict of values that will turn out to arise in their own health care. Families and other loved ones might disagree about what a patient would have wanted if the patient has explained her preferences to some but not all of the people who are close to her. Or, a proxy decision maker might only have long-ago conversations to guide her in determining what a person's loved one's preferences are, leaving her to wonder how that person's views might have changed over the intervening years.

Uncertainty might also arise because of changes in the patient that call into question the applicability of her previously stated preferences and values. Brain injuries, dementia, and some other personality-altering mental illnesses are characterized by shifts in values that complicate a proxy decision maker's task. For example, Agnieszka Jaworska describes a case of a man with dementia whose commitment to religious values formerly led him to prioritize a long life over any other considerations but who now expresses a desire to forego interventions that aim to extend his life.[64] As his dementia progresses, his religious commitments diminish in their importance to him, while his attachment to his wife and his grief over her recent death gain in priority. But, because of his dementia, he lacks the competence to make decisions on his own about his health care; he needs a proxy to make decisions on his behalf. This proxy decision maker must decide whether to honor his long-held values or respect his current preferences.

In this type of case, there is a surfeit of information about the patient's preferences, and some of the pieces of information are contradictory. Because, in this case and in others involving dementia or other personality-altering conditions, the changes are a result of the same illness or injury that calls into question the patient's competence to make health-care decisions, necessitating a proxy, it is difficult to know what is best for this patient. Is it better for her to honor her values and preferences before the shift? How ought the proxy understand the values currently expressed, given that the

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[64] Agnieszka Jaworska, "Respecting the Margins of Agency: Alzheimer's Patients and the Capacity to Value," *Philosophy & Public Affairs* 28.2 (1999), 107, 124.

patient lacks competence to make the decisions for herself?[65] In this kind of a proxy decision-making case, there is an overabundance of data about the patient’s preferences and values, but it is contradictory.

Cases involving small children and infants have the opposite problem. Rather than an overabundance of data, there is only an incomplete set of data about the patient’s preferences and values, or at least mature preferences and values, because the child has not yet developed to the point at which she can settle on her preferences and values for herself. As a child grows up, her personality emerges and tends to stabilize along with a fairly coherent set of preferences, values, and personal interests. So, as a child grows up and matures, the data set about preferences and values fills in, and the proxy decision makers have more information to inform their decisions, even as they are needed less over time to make decisions on the child behalf since she can begin to make more of these decisions for herself. Some indications of what is likely to matter most to the child and how she would want to structure her life can be present even from a young age, but parents who must make proxy decisions that will affect their child’s options do tend face an incomplete set of data about what preferences and values the child would prioritize if she were competent to decide for herself.

Cases involving parents or guardians deciding on behalf of small children and infants are not the only type of proxy health-care decision-making cases that are characterized by incomplete information about the patient’s preferences and values. Any patient who is incompetent to make a health-care decision for herself who does not have a proxy decision maker who is familiar with her preferences and values will also be in

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[65] Jaworska offers compelling answers to these questions (ibid., 105–138).

this category. For example, unconscious, unidentified patients will need a proxy to make decisions in their stead, but the proxy will not have the benefit of information about how this person would likely decide for herself about whether to accept or refuse certain courses of treatment.

Different-child choices in reproductive selection present the decision maker with an extreme version of the challenge of making a decision on behalf of someone else without access to a complete set of data about that other person's preferences and values. Different-child choices can be understood as proxy decisions for someone whose specific preferences, interests, and values cannot be known because they—both the person and the preferences, interests, and values—do not exist yet. The prospective parents do not have the benefit of any information about the possible children's particular personal values, preferences, and interests to help them make their decision. Yet, just as there is no single right answer for whether to keep all patients with a terminal condition on life support, so, too, there might not be any one right answer about different-child choices, even for one particular medical condition.

In different-child choices, selection might be the right tool to promote certain worthwhile values but not others, and the answer to the question of whether selection amounts to what is best for the child will depend on the specifics of individual cases. While the prospective parents do not have any information about their prospective children's personal preferences or values, they do have information about the family, their resources (financial, social, emotional, and so on), and their community, culture, and social institutions. That is, they have information about the initial situation a child would be created into, so they can consider how those factors would benefit or burden a child created with a certain genetic trait. Despite the fact that the yet-to-be-created child does not, and cannot, yet have any specifically personal interests, values, or preferences, there is no one way for all different-child choices to be made well, since what is a good decision in the context of one kind of initial situation is not necessarily a good decision in the context of a different initial situation. Because of the limits on the information available, proxy decision making in a different-child choice—or in any context in which there is only general information available, nothing specific to the patient's personal preferences and values—will look different than in the ideal case of the husband with stable, known preferences above. This is where the idea of a better or worse initial situation becomes useful for evaluating what would be better or worse for the child the prospective parents aim to create.

What is a good initial situation—or what is best for a child—depends on the particulars of the yet-to-be-created child's initial situation, including her family structure, her family's resources (broadly construed), her parents' personal strengths and weaknesses, attitudes toward her condition in her community, political, social, and environmental conditions in her geographical area, and on and on. In a different-child choice, the proxy decision makers, i.e., the prospective parents, should evaluate the options they have for initial situations they could bring a child—some child—into. This is an evaluation that can be made independently from any information about any particular child's particular preferences and interests, as indeed it must be made independent of those particulars since those particulars do not yet exist. Because the prospective parents cannot know in advance most of the traits any individual child they might create will grow up to have, the best they can do is evaluate the likely impact having a specific condition or genetic trait would have on any particular child in the specific context into which they are considering creating her.

For parents and prospective parents making health-care decisions for existing children and children who have yet to be created, there is a need to recognize the importance of encouraging development of new capabilities so as to protect children's interests in having and exercising those capabilities throughout their lives. Allen E. Buchanan and Dan W. Brock call this type of interests "developmental interests."[66] Because these children—existing and not yet existing—cannot decide for themselves, their guardians ought to exercise care not to preclude them from enjoying future opportunities and advantages that they might otherwise benefit from. Infants and children have a special interest in being allowed and encouraged to develop the abilities, talents, and skills that they, as human beings, typically have the potential to develop. So, those who decide for them have reason to make choices that protect and expand that potential where possible. In other words, something like Joel Feinberg's notion of a right to an open future[67] seems to apply in proxy decision making for children, infants, fetuses, embryos, and, by extension, even yet-to-be-conceived children that prospective parents aim to bring into existence.

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[66] Allen E. Buchanan and Dan W. Brock, *Deciding for Others: The Ethics of Surrogate Decision Making* (Cambridge: Cambridge University Press, 1990), 246–266. "Developmental interests" are defined on p. 247. Buchanan and Brock focus on newborn infants' developmental interests, but I take it older children and yet-to-be created children have similar developmental interests as well.

[67] Joel Feinberg, "A Child's Right to an Open Future," in *Whose Child? Parental Rights, Parental Authority and State Power*, ed. William Aiken and Hugh La Follette (Totowa, NJ: Littlefield, Adams, 1980), 124–153. See also Dena Davis, *Genetic Dilemmas: Reproductive Technology, Parental Choices, and Children's Futures* (New York: Routledge, 2001) for an approach to the ethics of reproduction that relies heavily on the importance of a child's right to an open future and Buchanan and Brock's brief discussion of the importance of respecting a child's right to an open future in proxy decision-making, *Deciding for Others*, 247–248.

Thus, in a case involving newborn, conjoined twins whose lives are at risk and at best only one can be saved, the question of which child to save ought to be decided in a similar matter to a case in which a woman is pregnant with multiple fetuses whose lives are at risk unless a reduction of the pregnancy is performed.[68] The newborn, conjoined twin case is a different-child choice in which the parents must rely on an evaluation of each newborn's situation despite the fact that the infants exist as children and not just embryos or fetuses because they, like embryos and fetuses, do not yet have known individual, personal preferences and values. If one newborn or fetus has a better chance of survival and better odds of flourishing than the other(s), then the parents do no wrong by selecting to save that fetus or newborn rather than the other(s). If there are no traits that convey one a better chance at a good life than the other(s), then they will have to fall back on other factors to decide, such as the relative safety of the medical procedure to save one rather than another or a coin toss. With older conjoined twins whose personal preferences and values were better established and better known, those preferences and values must be taken into consideration in a way that they cannot be with newborns or fetuses.

The goal of protecting developmental interests or an open future explains why treatment of serious medical conditions in infants and small children, in general and where possible, is not controversial despite the fact that they cannot competently consent for themselves. The justification for treating conditions that would otherwise limit a child's development or curtail her opportunities is, presumably, at least in part, that treatment keeps her options open and serves her developmental interests rather than

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[68] I thank Barbara Herman for encouraging me to address how to evaluate these cases.

limiting a child's range of possibilities before she is competent to consent to that limitation herself.

The developmental interests that infants and children have also count in favor of selecting to create a child only into an initial situation that is compatible with a reasonably wide range of opportunities to live a full, rich life. This consideration justifies many prospective parents' decision to wait until they are financially stable, in a healthy relationship with a prospective co-parent, and emotionally mature, say, before creating any children.[69] It can also contribute to justifications of both decisions to select and decisions not to select in the kind of different-child choices that are my main concern. To see why this is, consider the following cases.

For prospective parents with access to excellent medical testing and care, deciding to knowingly risk creating a child with phenylketonuria (PKU) by not making use of selective measures like IVF with PGD to prevent it might not violate the duty they have to protect and promote their child's developmental interests. PKU is a metabolic condition that is transmitted to offspring according to an autosomal recessive pattern, so if both parents are carriers of the relevant mutation then each of their offspring has a one in four chance of being affected by the condition. If untreated, children with PKU will not develop their intellectual capacities in the normal way because a metabolic byproduct

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[69] This consideration also explains why the young mother in Parfit's much-discussed case of the 14-year-old girl who wants to become a mother, (*Reasons and Persons*, 358), ought to wait before she becomes a parent. As the case is described by Parfit, the young girl is not currently able to provide a very good initial situation for her son, but she does not seem to wrong her son by creating him before she is prepared to be a good parent to him because of the non-identity problem. For further discussion of this case, see, for example, J. David Velleman, "Persons in Prospect," *Philosophy and Public Affairs* 36.3 (2008), 266–288; Matthew Hanser, "Harming Future People," *Philosophy & Public Affairs* 19.1 (1990), 47–70; and David Heyd, "The Intractability of the Nonidentity Problem," in *Harming Future Persons: Ethics, Genetics and the Nonidentity Problem* ed. Melinda A Roberts and David T. Vasserman (Dordrecht, London: Springer, 2009), 3–25.

will build up in their system, interfering with their development. But, if affected children are diagnosed at birth and they are able to successfully manage their phenylalanine levels by following a diet that is very low in phenylalanine, the amino acid that those who have PKU are unable to metabolize, then they can prevent these intellectual deficits.[70] Since, in this example, dedicated monitoring and management of the condition can usually protect a child's developmental interests, if the parents are willing and able to commit to that regimen, then they can satisfy the duty to protect and promote their child interests without having to make use of selection.

But, while some conditions can be managed, treated, or otherwise accommodated in some situations after an affected child is created, many other conditions cannot be at all or cannot be in the prospective parents' current situation. For a case in which prospective parents are at known risk for passing on a condition that cannot be managed or accommodated in order to avoid its negative effects on the child's developmental or other interests, the moral push to select against the condition is stronger in proportion to the degree to which the condition would negatively affect the balance of advantages and burdens in her initial situation. If the parents are unable by other means (or unwilling to commit) to provide an affected child with adequate opportunities to develop and pursue her interests so that she has a good chance to flourish, then they ought to select against the condition that will burden her.

At the extreme, for a devastating congenital condition like Tay-Sachs disease for which there is no treatment and no effective way to manage its effects and which has

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[70] Cederbaum, "Phenylketonuria: An Update," *Current Opinion in Pediatrics* 14.6 (2002), 702–6; U.S. National Library of Medicine, "Phenylketonuria," in *Genetics Home Reference: Your Guide to Understanding Genetic Conditions,* http://ghr.nlm.nih.gov/condition/phenylketonuria.

such a negative effect on a child's initial situation, selection seems required in cases in which there is a significant, known risk and there are safe, effective methods of selection that are not otherwise morally objectionable available. At the other extreme, a condition that is readily detected and easily treated or managed so as not to interfere significantly with the child's prospects for flourishing does not justify a moral requirement that the parents select, even if safe, effective, morally permissible methods of selection are available. In between, there are cases in which prospective parents ought to either select against the condition or commit to providing the treatment, care, and support required to manage and accommodate the child's burdens, allowing her a good chance at a full, rich life.

In summary, given that a child who does not yet exist cannot have preferences, priorities, and values of her own, "what is best for the child" is determined by the quality of the initial situation she would be born into, if created. The quality of the initial situation, in turn, depends on a wide range of factors, including but not limited to the physical burdens a child with a given medical condition would endure; the medical, social, emotional, and financial resources available to the family to allow them to treat, manage, and/or accommodate that condition; the prospects for a child in those circumstances to develop; and opportunities for her to decide and pursue her own interests and priorities. The evaluation of initial situations is complicated by the fact that there is no single way to live a good live, and so parents ought to do what they can to leave a child options to decide for herself which among a plurality of good lives she prefers to pursue. That is why there is no one answer to the question of the morality of selection, even for a particular medical condition. It depends on the evaluation of the initial situation, which depends on the effects of the presence or absence of that particular medical condition in the context of many other aspects of the situation.

6.2 Conclusion

Different-child choices in situations in which assisted reproductive technologies provide the means to select gametes, embryos, or fetuses that have (or do not have) a particular genetic trait are similar in morally relevant ways to other sorts of different-child choices. Decisions about when to start a family, how many children to have, how to try to space out those births can all be different-child choices. Yet, these kinds of different-child choices seem more mundane and less morally worrisome than prenatal testing and selective termination, selecting embryos for implantation on the basis of PGD results, and even sperm sorting. Why? Is it simply because they are more mundane, less dependent on sophisticated or new technology? Having options in family planning decisions about when and how many children to have can rely on sophisticated or new technology, so that does not seem to draw a moral line. Do these more familiar different-child choices leave more up to chance or to nature in a way that matters morally? Are they in some important way less deliberate than targeted genetic testing and selection? What marks these other cases as different-child choices is exactly that they are deliberate and not a matter of leaving reproduction up to chance or nature, so these possibilities cannot plausibly delineate a moral divide either.

No matter the level of technological sophistication required, there are some cases in which is it better for the child, in the sense that the initial situation will be better, if prospective parents make a choice to create a different child rather than the one who would be created without intervention. When that judgment applies because of the presence of a serious medical condition, the condition is one for which it would be better for an affected, existing child to treat the condition or manage its symptoms if that were possible. But, because current technology is better able to screen for or diagnose certain conditions and select against them using assisted reproductive technology than to treat them, there are cases of known, significant risk for which reproductive selection is the only way to prevent that condition from imposing undue burdens on a child.

Making good choices about reproductive selection in this kind of different-child choices requires prospective parents to take several factors into careful consideration. The morality of such choices depends, in part, on their attitudes toward the condition; their familiarity with it and its true implications, not just stereotypes or misguided assumptions about it; and their resources for managing, and even growing from, the experience of having a child with the relevant condition. It also, most importantly, depends on the implications of having that condition for the balance of advantages and burdens in a child's initial situation. If being affected by the condition in the full context of a child's initial situation would make her expected balance of advantages and burdens both tilted toward more burdened than benefited and worse than that of a potential sibling who could be created without the condition, then selection is permissible. In extreme cases in which the condition is devastating and the benefits and joys of life cannot justify the burdens simultaneously imposed, selection is required to avoid the parental failing of recklessness in procreation. In cases in which the improvement to the initial situation is due only to objectionable attitudes of the parents or society, selection is objectionable insofar as it is complicit with objectionable norms.

As Judith Jarvis Thomson writes about the ethics of another type of reproductive decision making, “there are cases and cases, and the details make a difference.”[71] While I cannot hope to settle the question of the ethics of all cases of reproductive selection here—not least because the answers are irreducibly context-dependent—I have endeavored to provide prospective parents a way of approaching the question of what is best for their child in these cases. They should decide as the child’s proxy decision maker, whichever child it might be, primarily on the basis of their evaluation of the possible initial situations into which they could create a child. They should select an initial situation that does not impose an overly burdensome start to the child and that protects and promotes her developmental interests. If the only way to do so is by making use of assisted reproductive technologies, then they should, since there is no inherent moral objection to those methods in themselves. The only legitimate moral objection to instances of selection will be objections on the basis of something other than the fact that the act is one of selection.

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[71] Thomson, “A Defense of Abortion,” *Philosophy & Public Affairs* 1.1 (1971), 58.

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