

EXPECTING EQUALITY

HOW PRENATAL SCREENING POLICY HARMS PEOPLE WITH DISABILITIES

Athmeya Jayaram

AT VARIOUS STAGES in the reproductive process, doctors offer prospective parents the opportunity to screen their embryos or fetuses (hereafter “embryos”) for genetic conditions that lead to future disability, such as cystic fibrosis and Down syndrome. When the screening comes back positive, the prospective parents—or “screeners”—then have limited information about the embryo: that it has a genetic condition and will have a future disability, or at least that it has a certain risk of developing one. If the screeners decide to terminate the embryo based on only this information, disability theorists argue, they are sending a harmful message to existing people with these conditions and disabilities. This is called the “expressivist objection” to screening and termination.

What message does it send? Defenders of the expressivist objection argue for two possibilities. S. D. Edwards offers an example of the first:

Consider a person currently living with cystic fibrosis. Such a person might hold the view that prenatal screening for cystic fibrosis, with a view to termination on grounds of the presence of cystic fibrosis in the fetus, sends a negative message to the person to the effect that it would have been better had he not been born.¹

In this example, terminating the embryo sends the message that, once it is known that an embryo has cystic fibrosis, it would be preferable that the embryo did not live than that it live with that condition.² This is supposed to imply that people with cystic fibrosis do not have lives worth living, which is a psychologically harmful message to people currently living with that condition.

1 Edwards, “Disability, Identity and the ‘Expressivist Objection,’” 418.

2 I use the neutral term “it” to avoid taking a position on whether embryos or fetuses are persons.

It can also be materially harmful if it strengthens the attitude that the lives of people with this and other conditions are not worth saving or extending, when the opportunity arises.

A second possible message seems initially less harmful, but may be more so because it is more relevant to daily life. Janet Malek, Adrienne Asch, and others argue that terminating an embryo based on a single characteristic sends the message that it is appropriate to evaluate and make significant decisions about a person (or future person) based solely on their disability. There are two ways in which one might arrive at this message. First, one might straightforwardly think that the disability is all one needs to know to evaluate the future person. As Malek puts it, “selecting against a future child on the basis of a disability signals that a disabling trait can be so significant and so undesirable that it eclipses all of the individual’s other traits.”³ Second, one might mistakenly think that a person who has one disability also has a host of others, which would lead one to conclude that a single disability is sufficient to evaluate a person. As Asch says, the “rehabilitation literature is full of examples of how able bodied people think of disabled people not as having specific disabilities, but as being *generally* incompetent.”⁴ In either case, however, the harmful message is supposed to be sent when an embryo is evaluated on the basis of the genetic condition alone. This message is harmful because it suggests that one should also evaluate the worth of current people with disabilities based solely on their disability, and not the many other aspects of their lives and character.

Theorists have offered three kinds of responses to the expressivist objection, each of which denies that screening and termination send any harmful message to people with disabilities. The first response argues that, as long as the screeners *could* be motivated to terminate the embryo by something other than the harmful judgments, the action does not send a harmful message. A second response claims that the action of termination is targeted at the genetic condition but not at the people who have it, so it does not imply anything about the worth of those people. A third response argues that the termination is motivated by the high costs of raising a child with a disability, rather than a judgment about people with that disability.⁵

3 Malek, “Deciding against Disability,” 217.

4 Amundson, “Disability, Handicap and the Environment,” 114n8, quoted in Asch, “Disability Equality and Prenatal Testing,” 329.

5 A fourth possible response concedes that screening and termination send a harmful message but that the harm is outweighed by its benefits. I will briefly address this concern at the end of the paper. However, this fourth response is largely in line with my argument, which is that the screening and termination of embryos with less severe genetic conditions sends a harmful message to people with those conditions, and that this harm gives us a *pro*

I will argue that the first two responses fail to answer the expressivist objection once we correctly understand when actions send harmful messages to their targets. It is not when the actor *could* have a harmless motivation or when the recipients identify with the targeted category. Instead, it is when a “reasonable person” would see the action as motivated by a harmful attitude.

However, the third response—that screening and termination may be motivated by cost—is reasonable. It is reasonable to see the screeners as motivated by the costs of raising a child with the disability rather than by a judgment about the disability or the people who have it. Nevertheless, this motivation still sends a message—different from the two suggested by disability theorists, but one that still causes harm. The message is that it is permissible not to pay a higher cost to support people with disabilities when there is a less costly abled alternative. This message echoes, sanctions, and reinforces the same attitude among public officials and employers, which has long motivated their refusal to provide people with disabilities with equal opportunity. In addition to affecting the rights and welfare of people with disabilities, this message also affects their sense of self-worth, or what John Rawls calls the “social bases of self-respect.”⁶

I further argue that this message is sent most clearly and harmfully by the state when it allows screeners to terminate because of cost considerations. It is reasonable to see this state action as motivated by the harmful attitude above for two reasons. First, as I will argue, the US government has a long history of failing to pay a higher cost to support people with disabilities, so it is reasonable to see the same motivation behind the refusal to regulate screening and termination. Second, there is no other reasonable and legitimate motivation for the government to allow screening and termination. As I argue through an analogy with sex-selective termination in India, it is not reasonable to see the government as motivated to respect reproductive rights because there is no right to information about one’s embryonic offspring. Nor, in certain cases, is it reasonable to see the government as merely serving citizens’ interests in avoiding the high cost of raising a child with a disability. Citizens only have this interest because of the government’s failure to fulfill its duty to provide equal opportunity to people with disabilities, so this failure cannot serve as a justification for further government action.

Now, I say “certain cases” because there are genetic conditions like cystic fibrosis that are so severe that no amount of government effort could equalize the costs to parents of raising a child with those conditions. (I will call such

tanto reason to stop screening for those conditions. I will therefore focus on evaluating the first three responses to the expressivist objection, all of which deny that screening and termination send a harmful message.

6 Rawls, *A Theory of Justice*, 386, and *Political Liberalism*, 318.

conditions “severe” in reference to the fact that the government cannot equalize the costs of raising a child with that condition.) In such cases, the government is not failing in its duty, so it is reasonable to see the government’s motivation as reducing the costs to prospective parents. For that reason, when the government allows the termination of embryos with severe genetic conditions, it does not send a harmful message to people with those conditions.

However, since the government *can* significantly reduce the costs of raising a child with a less severe disability such as Down syndrome, allowing screening and termination of these conditions does send a harmful message. (I will call such conditions “less severe” in reference to the fact that the government *can* (and should) equalize the costs of raising a child with that condition.) What message does the state send in allowing screening for less severe conditions? It sends the same harmful message that is evident in so many other government actions: Why pay the higher cost of supporting a person with disabilities, when you can just wait for an abled alternative?

1. FIRST RESPONSE TO THE EXPRESSIVIST OBJECTION: OTHER POSSIBLE MOTIVATIONS

The expressivist objection argues that prenatal screening and termination based on the genetic condition of an embryo sends a damaging message to people with that condition. To evaluate this claim, then, we need to know when an action sends a message. Allen Buchanan argues that an action (or decision) only sends a message when the action “presupposes” that message, either rationally or as a necessary element in one’s motivation.

Presumably, to say that a decision expresses (or presupposes) a judgment is to say either (a) that (as a matter of psychological fact) one could be motivated to make a decision of this sort only if one subscribed to the judgment (and that hence one couldn’t make the decision if one did not believe to be true what the judgment affirms), or (b) that one cannot rationally make the decision without believing what the judgment affirms.⁷

Under Buchanan’s view of what it is for an action to send a message, an action does not send a harmful message as long as we can think of a psychologically possible motivation, or rational alternative justification, for that action that does not send a harmful message. Buchanan then suggests several alternative motivations for terminating an embryo with a disability that do not send a

7 Buchanan, “Choosing Who Will Be Disabled,” 30.

harmful message: "one may simply wish to be spared avoidable and serious strains on one's marriage or on one's family. Or one may wish to avoid putting additional pressure on limited social resources to support disabled individuals. . . . [Or one may] desire not to bring into the world an individual with seriously limited opportunities."⁸ Screeners who act on these beliefs or motives do not necessarily express a claim that certain lives are not worth living or that lives can be evaluated solely based on a genetic disability.

However, this is an overly demanding requirement for an action to send a message. There is always another way to interpret an action that is psychologically possible and rational, and avoids attributing a harmful motivation to the actor. For instance, rather than attribute a sincere motivation to the offending actor, one can always see the action as ironic, sarcastic, or a parody, which completely changes the motivation we attribute.

This is especially true of actions that send a harmful message to the disadvantaged because the action can often be interpreted as a *concern* for the disadvantaged, as in calls for assimilation, racial passing, or conversion therapy. Many such calls clearly send a damaging message to members of the targeted group: that the way they are is not acceptable. However, it is always *possible* to interpret the sender's motivation as a concern for the targeted group. On this interpretation, the sender might be saying: "There is nothing wrong with being gay but, in our society, gay people face a life of discrimination so, out of concern for them, I think they should be "converted." This may be a misguided way of showing concern for gay people, but it is not irrational to see the sender as motivated in this way. So, unless we concede that calls for conversion do not send a harmful message, we need a different test than whether there is a harmless motivation that is psychologically or rationally possible.

If the problem with Buchanan's test is that it is always possible to reinterpret the motivations behind an action, then perhaps we should focus on the *actual* motivations of the sender. We could then say that if (and only if) the sender was actually motivated by a harmful judgment toward gay people then their actions send a harmful message. But this test goes too far in the other direction. A message can be sent regardless of the actual motivations of the actors involved. James Nelson offers the example of a group of people who raise the Confederate flag over the South Carolina State House. In this case, it does not seem to matter what their actual motivations are; the flag has a socially accepted meaning as a symbol of slavery and it is being used in a standard way to express that meaning.⁹ The flag raisers may actually be motivated by nostalgia or respect

8 Buchanan, "Choosing Who Will Be Disabled," 31.

9 Nelson, "Prenatal Diagnosis, Personal Identity, and Disability," 216.

for those who died in the Civil War. They may even, as I suggested earlier, be motivated to criticize the state's racist policies by associating the state with a racist symbol. But the very fact that this action *would* associate the state with racism means that the motivations of the actors do not matter to the message conveyed, since the message would be received as a racist one regardless of their actual motivations. The test of whether a message is sent must depend not on the sole possible or actual motivation for the action, but on how the motivation would be perceived.

But perceived by whom? How people interpret the display of the Confederate flag likely depends on whom you ask. A group of white Southerners may answer differently than a group of African Americans. This problem would be more pronounced in an even more racist time and place, like the antebellum South. At that time, the majority of people may have seen holding slaves as motivated by economic survival or ambition rather than racism. The perspective that interprets the message of an action should not simply reflect the social conscience of a society at the time. If it did, then a society in which the disadvantaged had internalized their lower status would not recognize any action as sending a harmful message. Instead, the perspective that attributes motivations to actions should be well-informed about how the proposed attitudes and actions fit into a larger historical pattern.

This more informed perspective will often be the perspective of the potential target of the message, since they are more likely to be aware of the pattern of actions and attitudes and less likely to try to rationalize away discriminatory attitudes. For example, as Sophia Moreau writes in trying to redefine the concept of "accommodations," there are many aspects of everyday life—such as the building of stairs instead of ramps—that are created to accommodate the abled in a way that may seem trivial to the designers and to most users.¹⁰ Just one less entrance accessible to people with disabilities, one fewer job. Given what they see as the small scale of the benefit, they may see themselves as motivated by a cost-benefit analysis rather than by any harmful indifference to the interests of people with disabilities. However, people with disabilities are much more likely to see the significance of the indifference behind these decisions because they experience a pattern of indifference, or worse, in so many other aspects of their lives.

There are two advantages to privileging the perspective of the targeted group. First, people with the targeted conditions will witness many more actions toward people like themselves by people like the senders and will therefore be in a better position to discern a pattern or common motivation behind

10 Moreau, "Discrimination and Subordination."

those actions. Where a screener may make only one decision concerning people with Down syndrome in a lifetime, a person with Down syndrome witnesses a lifetime of other people's decisions toward people like him.¹¹ Second, beyond personal experience, people with genetic conditions and disabilities are more likely to be aware of the history of treatment of people like themselves by people like the sender. People with disabilities are therefore better able to judge whether there is a historical pattern that provides evidence of the senders' likely motivation.

However, while this moves in the right direction, we should not take this too far. People with disabilities may have more experience with discrimination toward the disabled, but that volume of anecdotal evidence could also lead them to see discrimination too often; they may be understandably, but overly, sensitive. So, we need a standard that captures what is appealing about the perspectives of people with disabilities but provides some critical distance from that perspective as well.

Let us therefore call the desired perspective that of the "reasonable person." A reasonable person will not focus on the possible or actual motivations of the sender, but will think about how the sender's motivation would likely be seen. A reasonable person will further consider how the motivation would likely be seen in light of the historical pattern of actions and attitudes by people like the sender toward people like the target. This interpretation will be informed by, but not identical to, the targets' views of the action. A reasonable person will try to find the motivation that, in light of similar actions by similar people, as well as particular acts and statements by that person, best explains the action in question. In the case of genetic screening, we would want to know whether either of the harmful messages theorists have identified fits with the pattern of attitudes and actions exhibited by people like the screeners toward people with genetic conditions. If people like the screeners tended to show a great deal of concern for people with disabilities in their other actions, and even said so publicly, then it would not be reasonable to see them as motivated by a harmful attitude.

As always with "reasonable person" standards, privileging this perspective does not give us an obvious answer to whether screening and termination sends one of the harmful messages. To see whether it does, we will have to think more carefully about who is performing the action and what they (and people like them) have done in the past. However, identifying this perspective is an

11 Of course, it is also possible that people with conditions that impair cognition may not notice the patterns as well as others, which is another reason not to identify the right perspective too closely with the targeted group, but rather with a "reasonable person" who is aware of the experiences and history of the targeted group.

improvement on Buchanan's test. Buchanan denies that we ought to privilege any single interpretation of motive since there are many rational possibilities. If this were right, then even clearly harmful actions like advocating conversion therapy would not send any particular message. Privileging the perspective of the reasonable person helps us to identify clear cases of expressive harm, ones where any reasonable person would see an action as at least partly motivated by a harmful attitude.

The reasonable person standard also helps explain examples like the Confederate flag case. We can now say why it does not matter if the flag runners were actually anti-racist activists who sought to associate the state with a racist symbol. Unless it would be clear to a reasonable observer that the act was motivated by anti-racism—because, for instance, the flag raisers have an anti-racist track record and publicly stated their intentions—a reasonable person cannot be expected to see the act as it was intended. Instead, a reasonable person will see white people displaying the Confederate flag and come up with the most likely motivation for that action, based on a thorough knowledge of similar people performing similar acts. Based on all of this, a reasonable person would conclude that raising the Confederate flag appears to be motivated by racist attitudes, which therefore sends a harmful message to African Americans. By applying a similar analysis to screening and termination, I will argue that it does send a harmful message, but only one sent by the state to people with less severe disabilities. Before turning to that argument, however, I will consider two other responses to the expressivist objection.

2. SECOND RESPONSE:

TERMINATION TARGETS CONDITIONS, NOT PEOPLE

With this standard for when a message is sent, we can now apply it to the central question: Would a reasonable person see prenatal screening as sending a harmful message to people with the screened genetic conditions? Critics of the expressivist objection may still say no. For these critics, prenatal screening may imply a negative judgment on a genetic *condition*, but it need not say anything about the people who have that condition. Take cystic fibrosis (CF) for example. If you screen for CF and then terminate the pregnancy based on a positive result, you are clearly saying that you do not want a child with CF. But that does not express a judgment about people with CF any more than a flu vaccine expresses a judgment against flu sufferers. In the latter case, at least, a reasonable person would conclude that you are against the condition, not the people.

The first response to this objection is that there is a major difference between people with CF and flu sufferers; the flu is not identity constituting. Flu sufferers

do not think of themselves as such, and so would not take offense to a judgment against the flu. But at least some people with CF conceive of themselves as people with CF or, more generally, as people with a disability, so a judgment against the condition is also a judgment against the group of people who have it.

The problem with this response, the objector continues, is that it is not available to some defenders of the expressivist objection, such as Adrienne Asch. Asch argues that screening and termination send the second harmful message described above: that it is acceptable to evaluate people based on disability alone. The problem with that message, she argues, is that it reduces people to their disabilities. In making that argument, however, Asch seems to deny that disability is identity constituting. As Malek puts it:

Asch, the most consistent proponent of the expressivist argument, states that “disability is not, and need not, be either a ‘deep’ or a valued part of identity for everyone who shares the disability critique.” In fact, her primary objection to the use of [reproductive and genetic technologies] to prevent disability in future children is that such use suggests a reduction of disabled people to their disabilities. She therefore clearly *rejects* the idea that disabled individuals should be defined by their disabilities.¹²

If defenders of the expressivist objection must deny that disability is identity constituting, then they cannot use identity to differentiate between people with CF and flu sufferers. If this is right then, for both genetic conditions and the flu, targeting the condition does not target the person who has it.

This critique helps clarify the expressivist objection but is by no means fatal to it. Defenders can respond in several ways. The first is to affirm that disability is identity constituting but argue that this is consistent with the expressivist critique. This is most easily done by rejecting the second harmful message and focusing on the first. They may reject the suggestion that there is anything wrong with evaluating a person based on a disability and instead focus on the message that a life with a disability is not worth living. Since there is no contradiction between seeing *this* message as harmful and believing that disability is identity constituting, the expressivist objection still holds.

But one does not have to reject the second message to be consistent with the claim that disability is identity constituting. Defenders like Asch can insist that both messages are harmful, while holding that disability is only *partially* identity constituting. Recall that the second harmful message is that it is appropriate to evaluate a life based solely on a disability. Critics argue that rejecting this message is equivalent to rejecting the claim that disability is identity constituting.

12 Malek, “Deciding against Disability,” 219.

There are, however, two ways in which disability might be identity constituting. In the first, a disability is the most important part of one's identity; it defines a person to the degree that it is appropriate to evaluate that person based on the disability alone. That is the sense of "identity constituting" that people like Asch must reject when they object to the second harmful message. But there is a second sense of identity constituting in which disability is *part* of one's identity but not necessarily the most important part. Unlike flu sufferers, people still see their disabilities as an essential part of who they are and would acknowledge that, without their disability, they would be a different person. But acknowledging all this is not equivalent to endorsing the message that it is appropriate to evaluate a life based solely on its disability; that would be overly reductive in the way the critics point out. Instead, defenders of the expressivist objection can maintain that disability is part of people's identities and so a part of understanding them, while objecting to evaluations based solely on disability.

So, one way to show that targeting a disability is not the same as targeting the flu is to claim that disability is (at least partially) identity constituting, and one can do so in a way that is consistent with the expressivist objection. But even if one denies that disability is identity constituting, there is another important difference between targeting the flu and targeting disabilities.

When people "target the flu" with a flu vaccine, they do not *see* the flu as identity constituting—as part of who people are. Contrast this with screeners, at least some of whom will see disability as a part of people's identity.¹³ So, when those screeners decide to terminate the embryo because of its future disability, they are more likely to see that disability as part of the future person's identity. In that sense, some screeners "target" the disability, in a way that flu vaccinators do not. So, even if we deny that disability is, in fact, partially identity constituting, if the screeners *think* that it is, then their action may still send a harmful message to people with disabilities. If screeners see disability as part of people's identities, a reasonable person would still recognize that they are motivated by a harmful attitude toward people with that disability.

To take another example, when parents terminate an embryo based on the fact that it would be their third child, no message is sent to third children everywhere because neither third children nor the parents see that characteristic as part of their identity. But in the case of disabilities, screeners may see disability as an essential aspect of those who have one and still decide to terminate based on that characteristic. So, if you share that characteristic, even if you do

13 For instance, significant numbers of Americans think people with Down syndrome should attend different schools or workplaces, suggesting that having Down syndrome is very important to how one is seen and treated; Pace, Shin, and Rasmussen, "Understanding Attitudes toward People with Down Syndrome."

not associate with others on that basis or consider them to be “like you,” you could object to the attitude expressed toward people with that characteristic. As Nelson argues, if we started screening out future bald men, the existing bald men may well complain, even if neither bald men nor others saw them as a group before.¹⁴ The strength of their complaint would depend on the degree to which others generally see bald men as a group, treat baldness as identity constituting, and tend to express negative judgments toward it—in other words, the degree to which a reasonable person would see the message as directed toward bald men. However, a message could be sent regardless of whether bald men see their baldness as part of who they are. This is the nature of identity: one cares about it whether it is self-conceived, socially ascribed, or some combination of the two. An insult to a socially ascribed identity is still an insult.

There are therefore two important ways in which, unlike the flu, targeting a disability also targets people with that disability. The disability may be part of people’s identity or, even if not, screeners may *think* that it is. Either way, the expressivist objection still holds.

3. THIRD RESPONSE:

TERMINATION TARGETS CONSEQUENCES, NOT PEOPLE

While the expressivist objection survives the first two responses, a third one is more successful. Critics may argue that, in screening and terminating, screeners are rarely motivated by a harmful judgment against particular disabilities or the people who have them. Instead, screeners are often motivated to avoid the *consequences* of a future child’s disability.

The expressivist objection claims that, when screeners find out about the embryo’s genetic condition, that condition is all that they know about the embryo. So, if they decide to terminate the embryo, they must be sending a message about the genetic condition and disability, since that is all they know about the embryo. However, critics may say, that is not strictly true. Screeners know about the presence of a genetic disability *and* the likely consequences of that disability. They know that it will require more time, money, and effort to raise that future child, and those are the considerations that motivate them—not the condition itself. If the screeners decide to terminate because of such ordinary concerns, critics may say, they are not sending a harmful message any more than any other parent who decides to terminate on similar grounds.

For example, if you consider the benefit of having a child to be worth spending a certain amount of time or money, and you come to find out that it will

14 Nelson, “Prenatal Diagnosis, Personal Identity, and Disability,” 219.

actually require a lot more, you may change your mind about having a child. As Nelson argues, the same may happen if you lose your partner or your job; your ability to provide for children may no longer be equal to the cost of raising them, and so you may change your mind.¹⁵ But, in doing so, you are not relying on a judgment about the worth of the potential child—just a judgment about the costs you are willing to bear. Many people do not want to have children at all, and they are not seen as sending a message to existing children.

What harmful message is sent by deciding that one does not want to pay a higher cost to bring a person with disabilities into the world? Whatever message it sends, it does not fit either of the messages that disability theorists have proposed. It does not imply that people with disabilities do not have lives worth living, since it is a judgment about whether to pay the cost of raising future children with disabilities, rather than a judgment on the quality of their lives. Nor does it seem to evaluate a life based on disability alone, since it focuses on the costs of that disability and how those costs might affect the parents' lives.

Nevertheless, there is a third kind of harmful message that theorists have not yet identified—one that is compatible with being motivated by cost. Consider an analogy with sex-selective termination. India and China (and many other developing countries) have had a long-standing problem with selective termination of female embryos and fetuses, which has caused an imbalance in the male-to-female ratio.¹⁶ This imbalance continues today, despite both countries passing laws making it illegal to find out the sex of the embryo before birth. There are multiple causes of sex-selective termination and they are hard to disentangle. The economic disadvantage of having a female child is both caused by, and reinforces, the cultural disadvantages that women suffer in these societies. Nevertheless, at least part of the cause is economic.¹⁷ Here are a few of the economic factors that screeners must consider:

Inheritance and land rights pass through male heirs, aging parents depend on support from men in the absence of national security schemes and greater male participation in the workforce allows them to contribute more to family income. Women, on the other hand, require dowries and leave the natal family upon marriage, which make them an unproductive investment.¹⁸

15 Nelson, "Prenatal Diagnosis, Personal Identity, and Disability," 218.

16 Abbamonte, "Sex-Selective Abortion in India"; and Gupta, "Return of the Missing Daughters."

17 Hesketh and Xing, "Abnormal Sex Ratios in Human Populations," 13272; Myers, "Sex Selective Abortion in India"; and Gupta, "Return of the Missing Daughters."

18 Barot, "A Problem-and-Solution Mismatch."

The lack of economic opportunities for women in these societies, along with the lack of social programs to address this inequality, make it far more costly for parents to have a daughter than a son.¹⁹

When screeners in these countries decide to terminate female embryos, it is therefore reasonable to think they are motivated partly by cost. But the judgment this motivation expresses is still a harmful one: it is permissible (and perhaps even preferable) not to bear the higher cost of supporting a female child when one could support a male for less. This attitude is both pervasive and harmful. Parents express this attitude when they invest in their sons' educations, while keeping their daughters out of school, often doing unpaid housework.²⁰ The result is the denial of equal opportunity in education and employment: only 68 percent of women can read or write, compared to 87 percent of men, and women make up only 25 percent of the labor force in India.²¹ Because of the social and economic conditions in these countries, women will not have equal opportunity unless the society agrees to bear the higher cost (because of the lower return) of investing in them. So, a judgment that women are not worth this higher cost when there is a male alternative is a judgment against equal opportunity.

Screening and termination based on disability sends a similarly harmful message, even when it is motivated by cost. Under current conditions, equal opportunity for people with disabilities will require society to bear a higher cost to support them, even when there is a less costly, abled alternative. For people with disabilities to receive an equal education and equal opportunity for jobs, school administrators and employers must have the opposite attitude: that they should bear the higher costs to provide "reasonable accommodation" even when they could support an abled person for less. This attitude is also important for the self-worth and rights of people with disabilities: it encourages them to disclose their disabilities to their employers without fear of being replaced, and then to sue for their rights if they are. The enforcement of the Americans with Disabilities Act, which requires employers to provide reasonable accommodation, depends on lawsuits to promote justice. If people are afraid to disclose their disabilities or get the message that society prefers not to pay a premium to accommodate them, they are unlikely to advocate for reasonable accommodation. This message also potentially implies that people

19 Gupta, Zhenghua, Bohua, et al., "Why Is Son Preference so Persistent in East and South Asia?"

20 Barcelos, "Child Gender and Parental Investments in India"; National Commission for Protection of Child Rights, *Vocational and Life Skills Training of Out-of-School Adolescent Girls in the Age Group 15–18 Years*.

21 Abbamonte, "Sex-Selective Abortion in India."

with disabilities are not entitled to other rights, such as access to health care. Equal access to health care requires employers or the government to pay a higher cost to promote the health and opportunity of people with disabilities, even when those same resources could provide for a greater number of abled people. In these ways, the unwillingness to pay a higher cost to support people with disabilities is almost as harmful to the rights, welfare, and self-worth of people with disabilities as a judgment that their lives are not worth living or that it is appropriate to evaluate a person based on disability alone.

The attitude that it is permissible not to bear the higher costs of supporting a person with disabilities is clearly harmful, but is it reasonable to attribute this attitude to the screeners? The attitude is certainly pervasive among decision makers in the United States. Employers, for instance, are often unwilling to pay the higher cost to accommodate people with disabilities, resulting in wide gaps in employment. Only 33 percent of people with disabilities of working age are employed versus 77 percent of people without disabilities.²² And the gap remains even among those who are clearly capable of cognitive work: 30 percent of college-educated people with disabilities are employed, versus 77 percent of college-educated people without a disability. The cause of this gap appears to be employers' attitudes toward applicants with disabilities, which is in turn caused by the requirement to provide them with reasonable accommodation.²³

Despite this widespread attitude, it may not be reasonable to attribute this harmful motivation to individual screeners. There is a more targeted motivation that seems equally reasonable but far less damaging. Rather than saying that individuals are motivated to screen and terminate by not wanting to pay a premium to support a person with disabilities, we may say that individuals are motivated by a narrower belief: that the lives of people with disabilities are not worth the extra cost when we have the option of *bringing into existence* a less costly individual. If this were the motive behind the action, then it would not send a harmful message to currently existing people with disabilities since it would not imply anything about whether *existing* lives are worth the extra cost. It would only be a judgment about how to evaluate future lives, one with a disability and one without.

The second issue with judging individual screeners is that, even if it were reasonable to attribute a harmful motivation to them, this only gives them a *pro tanto* reason not to terminate the embryo. They may still have a stronger reason

22 Bureau of Labor Statistics, "Persons with a Disability," 2021.

23 Ameri, Schur, Adya, et al., "The Disability Employment Puzzle"; and Jolls and Prescott, "Disaggregating Employment Protection."

that would make it ethically permissible, all things considered, to terminate, such as when the costs of raising a child with disabilities is prohibitively high. It may be a harmful message for an individual to say that the cost of supporting a person with a disability is too high, but when that cost is high enough, it may be too burdensome to expect individuals to refrain from sending that message. To return to the example of sex-selective termination, some poor families in India and China simply cannot afford to pay a premium to have a female child, so their reason to terminate the embryo may outweigh their reason not to send a harmful message. Similarly, it might be too burdensome to expect individuals to take on (what can be) a high cost of supporting a child with a disability. The Americans with Disabilities Act, for instance, only requires employers to provide “reasonable” accommodation when it is not an “undue hardship” on their business.

These are strong objections to assigning an ethical obligation to individuals to refrain from terminating embryos because of their disabilities. And they may be right; this is the inherent difficulty in determining when an ethical obligation is overly burdensome or in how a reasonable person would interpret a motive. Nevertheless, we get a much clearer answer when we consider another actor: the state.

4. THE STATE

States send a more harmful message to people with disabilities than individual screeners for two reasons: (1) it is more reasonable to see this message in the overall pattern of most states’ actions, and (2) unlike many individuals, states—at least the wealthier ones—have the means to avoid sending a harmful message. I will begin by arguing these claims with regard to sex-selective termination in India because most people will find it more intuitive that termination based on sex sends a harmful message. I will then argue that there is only one relevant difference between sex-selective termination in India and disability-selective termination in the United States. Because of this difference, I conclude, the US government only sends a harmful message when it allows the termination of *less severe* genetic conditions such as Down syndrome.

For both sex- and disability-selective termination, the argument will proceed as follows:

1. When the government allows selective termination, it performs an action that can send a message.
2. Based on the history of similar government actions, a reasonable person would see the motivation behind allowing selective termination as based on a harmful attitude.

3. There is no other plausible, legitimate, and harmless motivation that would be more reasonable to attribute to the government.

Beginning with the first claim, then: When the Indian government previously allowed sex-selective termination, was this an action? You might think it was not. After all, the government merely *allowed* doctors to provide information and patients to act on it, without endorsing either practice. This is similar to the government allowing free speech, without endorsing the content of that speech. Does the government send a message when it merely allows screening and termination? The answer depends on whether the government claims regulatory authority over the practice. The difference with free speech is that liberal governments have no regulatory power over (most) speech; it is beyond their purview. So, when the government does not regulate speech, it is not because it has evaluated the speech and allowed it to proceed. Rather, the government does not even consider the question of regulating it.

Initially, one may think something similar about screening and termination: just as the government respects the right to free speech by not considering whether to regulate it, the government respects the right to reproductive freedom by not considering whether to regulate it. However, the scope of free speech is far broader than reproductive freedom. Just about all speech is allowed because it is not the government's role to decide which speech should be free and which should be regulated. Reproductive freedom, on the other hand, has limits. Those limits are contested, but few think that the government has no regulatory role in deciding what kind of information prospective parents can have about a future child. If we could determine them, should we tell parents about the intelligence, athleticism, or beauty of a future child? One could argue over the wisdom of doing so, but the debate would not be about the parents' right to know.

In any case, both the Indian and American governments *do* claim regulatory control over selective termination—most obviously, in the Indian case, as the government has now prohibited parents from knowing the child's sex in advance.²⁴ If the government has regulatory control over the activity and chooses not to regulate it, it performs an action that can send a message.

What message it sends depends, as I have argued, on how a reasonable person would see the motive behind the regulatory action. And a reasonable person interprets motive based on what best explains this and other government actions toward women. A reasonable person would be aware that the Indian government has passed some laws to promote equal opportunity for

24 Andrews, Fullarton, Holtzman, et al., "Assessing Genetic Risks."

women, but has done very little to implement or enforce those laws.²⁵ A reasonable person would also be aware that there is much more that the government can easily do to promote equal opportunity in ways that would discourage sex-selective abortion: change inheritance practices, punish families for demanding dowries and dowry-related violence, incentivize families to have only daughters, as well as the basic requirement to enforce and monitor the success of the policies already on the books.²⁶ And, unlike individuals, the Indian government has the means to enact, fund, and enforce these policies on a broad scale. So, based on the history of inaction by the Indian government to promote equal opportunity for girls and women, a reasonable person would clearly attribute a harmful attitude to the state: that it is at least permissible not to pay the higher cost of providing equal opportunities to women when there are male alternatives.

How does this general pattern of actions and attitudes relate to sex-selective termination? Many prospective parents who decided to terminate based on the sex of the embryo did so because of this same harmful attitude: they were unwilling to pay the higher cost of raising a female child.²⁷ The Indian government had access to the same reports that this attitude was a major cause of sex-selective termination, but it neither did enough to reduce this financial motivation (by providing equal opportunity), nor did it enforce the ban on prenatal sex determination for many years.²⁸ What was the most reasonable explanation for these government (in)actions? It was not a concern for the reproductive freedom of its citizens. As I previously noted, the Indian government claims regulatory control over information like the sex of the embryo, so it did not consider selective termination a right that was beyond evaluation. Nor, unlike for many individuals, was the motivation the prohibitive cost of supporting female children. In this case, the cost to the government was merely the cost of prohibiting sex-selective termination, which was, and is, within its means. So, the most reasonable explanation for the government's permitting sex-selective termination is therefore the same explanation for its failure to

25 Basu, *Harmful Practices against Women in India*; and Menon-Sen and Kumar, *Women in India*.

26 Gupta, Zhenghua, Bohua, et al., "Why Is Son Preference so Persistent in East and South Asia?"; World Health Organization, *Preventing Gender-Biased Sex Selection*; and Abbamonte, "Sex-Selective Abortion in India."

27 See notes 20–21.

28 Abbamonte, "Sex-Selective Abortion in India," 31.

equalize opportunity for women: an attitude that it is permissible not to pay a higher cost to support equal opportunity for women.²⁹

Now, one might still object that there is another reasonable motivation behind the state action that does not send any message to women. One might argue that the government is not claiming that it is permissible to refuse to pay a premium to support women; it is simply furthering the interests of its citizens. Citizens have an interest in selective termination of female embryos because of the extra time, money, and effort required to raise them. They prefer not to pay the extra cost of bringing a female child into the world when there is a less costly male alternative. Because the state has a *pro tanto* reason to further the interests of its citizens, the state ought to make it permissible to screen and terminate based on sex. Since this motivation is purely to further the interests of citizens, it sends no harmful message to women about whether it is worthwhile to pay a premium to support them or whether the state endorses termination. However, this “neutral” justification is not available to the state, so it is not reasonable to see this as the state’s message. Consider, again, the steps of the justification:

1. In Indian society, women face unequal opportunities that make it more costly and difficult to raise a female child.
2. Because of these additional costs, some citizens have an interest in terminating female embryos.
3. The state ought not to interfere with actions that further the interests of its citizens, as long as failing to interfere does not conflict with any other moral requirement.
4. Therefore, the state ought not to interfere with the selective termination of female embryos.

The problem with this argument is that the societal inequality for women might be a good reason for individual citizens to perform (or refrain from) an action,

29 The state’s inaction may send an even more harmful message: that selective termination of embryos with disabilities is not just permissible, but desirable. Consider the analogous situation of employers. If an employer failed to provide equal opportunity to women by, let us say, not providing maternity leave, and the employer was aware that this led to fewer female employees, it would be reasonable to infer that the employer intended and welcomed this result. Similarly, when the state fails to provide equal opportunity for people with disabilities, it increases the cost to individuals of raising children with disabilities. It is reasonable to think that increased cost motivates individuals to terminate embryos with disabilities. If the state is aware that its inaction leads to selective termination, and continues to allow the practice, it is reasonable to think that the state intends this result. This sends the far more harmful message to people currently living with disabilities that their lives are unwelcome or discouraged by the state.

but it cannot be a good reason for the state to do so. This is because the state has a duty to redress that inequality. So, from the state's perspective, the fact of the inequality cannot serve as support for any actions other than redressing that wrong.

More generally, I am arguing that if a person or entity has a duty to right a wrong, and is in a position to do so, its failure to right the wrong cannot justify any further decision. This is because, if an entity has a duty, and is in a position, to right a wrong, and yet uses its failure to justify some further decision, the entity is acknowledging that it will not fulfill its duty. This acknowledgement is unjustified, so it cannot justify any further decision.³⁰

To make this clear, let me spell out the attempted argument:

1. The state has a duty, and is in a position, to address unequal opportunities for women.
2. The state is not going to perform its duty.
3. Because the state is not going to perform its duty, citizens have an interest in selectively terminating female embryos.
4. Because citizens have an interest in selectively terminating female embryos, and the state has reason to further its citizens' interests, the state has reason to allow selective termination.

Again, however, the state cannot make this argument because it cannot justify the second step: refusing to perform one's duty is not justified and so cannot transfer any justification to the conclusion. The only claim that a refusal can justify is an attempt to fulfill one's duty or to compensate those who are owed the duty.³¹

30 This claim takes a position in the actualism versus possibilism debate. It is beyond the scope of this paper to defend my position in this debate, but I note it for those who hold the opposing view.

31 Here, one might object that there is a relevant difference between the state and an individual; the state is not a unified entity. So, while one part of the state fails to perform its duty to equalize opportunity, another part of the state may simply be responding to that failure. If this is right, then there is no internal contradiction when the Food and Drug Administration (FDA) allows screening and termination, because it is not acknowledging its failure to perform a duty, but is simply responding to the rest of the government's failure and trying to make the best of a bad situation. It is certainly possible that, while one part of a government is motivated by harmful attitudes toward women or people with disabilities, another part is clearly motivated only to help these groups. Perhaps the head of the FDA has a disability and is (shockingly) independent from the rest of the executive branch. In such cases, a reasonable person might see the FDA's motivation differently from the rest of the government's. However, as a consequence of the "reasonable person" analysis, such cases will be rare. Unless a reasonable person would have clear evidence to the contrary, we can attribute a harmful motivation to the FDA because it is reasonable to assume that FDA

So, government failure to equalize opportunity for women serves two purposes in this argument. It makes it reasonable to attribute a harmful message to the government in allowing sex-selective termination. And, it also makes it unreasonable to see the government acting on a harmless motive in which the government is simply furthering the interests of its citizens. Unless we can find an alternative justification for allowing sex-selective termination that is both reasonable and does not send a harmful message, there is a *pro tanto* reason not to allow the practice. It would send the harmful message to women that it is permissible not to pay a higher cost to provide them with an equal opportunity.

For the same reasons that the Indian government sends a harmful message to women when it allows sex-selective termination, the US government sends a harmful message to people with certain disabilities when it allows disability-selective termination. As before, the first step in the argument is to establish that when the US government allows disability-selective termination it acts in a way that can send a message. Like the Indian government, US government agencies like the Food and Drug Administration (FDA) and the Centers for Medicare and Medicaid Services claim regulatory authority over prenatal genetic testing, so leaving these decisions to doctors and patients is a *decision* not to intervene. More specifically, the FDA claims “enforcement discretion” to regulate genetic testing, which means it “has the authority to regulate tests but chooses not to.”³² And the government is clearly aware of the harm that choosing not to regulate genetic testing can cause: the National Council on Disability issued a report calling for more active regulation.³³ In some cases, the government approval is more explicit: Medicaid often covers the cost of genetic screening, which is a direct endorsement of its permissibility.³⁴ So, the US government’s refusal to regulate genetic screening and termination is an action that can send a message.

Next, I will argue that a reasonable person would see this government choice as sending a harmful message to people with certain disabilities for two reasons. First, there is a larger pattern of government action and inaction toward people with disabilities that suggests a common and harmful motivation: that it is permissible to fail to pay the higher cost of supporting people with disabilities when there is a less costly abled alternative. I have already discussed the lack of equal opportunity in employment, which is partly a result of poor government enforcement of laws requiring reasonable accommodation. One

officials are similar to other government officials, and the overall pattern of their actions is the same.

32 National Human Genome Research Institute, “Regulation of Genetic Tests.”

33 National Council on Disability, *Genetic Testing and the Rush to Perfection*.

34 Andrews, Fullarton, Holtzman, et al., “Assessing Genetic Risks.”

study found that “47 to 58 percent of accommodation-sensitive individuals lack accommodation and would benefit from some kind of employer accommodation to either sustain or commence work.”³⁵ And while progress has been made, many public buildings are still not accessible to people with disabilities.³⁶ For instance, two-thirds of schools still have physical barriers that limit access for people with disabilities, as do many forms of public transportation and public housing.³⁷ Most important for this discussion, there is also unequal (and likely inadequate) access to special education teachers in public schools, increasing the financial and emotional costs of raising a child with a disability, particularly for poor communities.³⁸

Second, there is no other legitimate and plausible motivation that would more reasonably explain the government’s allowing disability-selective termination. As before, the most obvious candidates are reproductive freedom and innocently serving the interests of citizens. Regarding reproductive freedom, the US government rejects any individual right to information regarding the genetic condition of the embryo when it claims the ability to regulate it. And the claim that the government is merely serving the financial interests of its citizens faces a similar problem as the analogous claim for sex-selective termination. For the government to claim this motive, it would have to acknowledge that it will not do its duty to equalize opportunity for people with disabilities, which would reduce the financial motivation for selective termination. Since the failure to perform a duty cannot justify any further action (other than compensation), it would not be reasonable to attribute this harmless motive to the government.

While the analogy generally holds for sex- and disability-selective termination, there are two potential differences. The first is that some may accept the claim that the government has a duty to equalize opportunity for women, but deny that it has a duty to equalize opportunity for people with disabilities. I cannot defend the latter claim here, but if the reader rejects it, then my analogy fails as well. The second difference is, however, a relevant one. As I have mentioned throughout, I am arguing only that the state sends a harmful message when it permits selective termination of embryos with *less severe* disabilities. I can now explain the reason for this limitation in the case of disability-selective termination.

35 Maestas, Mullen, and Rennane, “Unmet Need for Workplace Accommodation.”

36 Silvestrini, “The Americans with Disabilities Act at 30.”

37 US Government Accountability Office, “K-12 Education”; Piekarski, “Major American Cities Still Pose Problems for People with Disabilities.”

38 Mason-Williams, “Unequal Opportunities.”

The argument works for both sex- and disability-selective termination because the government's failure to equalize opportunities for women or the disabled makes the cost prohibitive for some screeners, leading them to terminate the embryo. This applies to all cases of sex-selective termination because it is *possible* for the government to equalize opportunities between men and women in all aspects of their lives. There are no inherent differences between the sexes that would explain the inevitable added costs of raising a daughter, so the government is theoretically able to equalize the costs and opportunities for both sexes.

However, this is not the case for people with severe genetic conditions. Some impairments are severe enough that, while the government can reduce the cost of raising a child with that impairment, it cannot make the cost non-prohibitive for many screeners. So, screeners who have embryos with severe genetic conditions will retain an interest in selective termination, whether or not the government fulfills its duty. In those cases, the government's justification does not rely on its own failure to perform its duty, which means there *is* a neutral justification available for allowing selective termination: serving its citizens' interest in avoiding prohibitive costs. So, when the government permits screening and termination of severe genetic conditions, it does not send a harmful message to people with those conditions, it merely recognizes that individuals have an interest in not bearing a prohibitive cost to raise a child—a cost the government cannot meaningfully reduce. The practical implications of this argument will depend on the details of the genetic condition in question and what the government can do to reduce the cost of raising a child with the resulting disability.

As an illustrative example, we can think of the difference between a fetal diagnosis of cystic fibrosis (CF) and one of Down syndrome (DS). The material and emotional cost of CF is enormous. A severe case is estimated to cost almost \$3,000 a month in health care costs and require two to three hours a day for treatment.³⁹ People with CF live an average of forty-seven years.⁴⁰ It would be impossible to equalize opportunity for people with and without CF, or to equalize costs to parents of children with and without CF, so individuals would have an interest in avoiding these costs regardless of the state's assistance. The government therefore has a harmless motivation for allowing screening and termination for CF.

Many cases of DS are quite different. The estimated out-of-pocket expenses average only \$84 per month, and many people with DS live fulfilling lives, with

39 Van Gool, Norman, Delatycki, et al., "Understanding the Costs of Care for Cystic Fibrosis"; Cystic-Fibrosis.com, "Managing Daily Routines and Treatment Schedules with Cystic Fibrosis."

40 Farber, Prieur, Roach, et al., "Difficult Conversations."

a life expectancy that is approaching the average American without a disability (sixty-five versus seventy-nine years).⁴¹ With a concerted government effort, one could imagine that life expectancy could eventually be similar. Even if not, it is not a significant added burden to individual screeners, since the child with DS is still likely to outlive the parents. The government could also narrow the additional cost in time and effort to raise a child with DS by providing educational and care assistance, in school or at home. If the government pushed to equalize opportunities for people with DS, screeners might no longer have an interest in avoiding the additional costs. In a case like this, there is no non-harmful motivation for allowing screening and termination. The only possible harmless motivation is invalidated by the government's failure to equalize opportunities for people with this disability.

Now, in making this argument, I have claimed that the state has a duty to provide equal opportunity to people with disabilities and is failing to fulfill that duty. One might therefore say that I have started with a big problem in order to point out a small one. The real problem is the state's failure to provide equal opportunity, so it is comparatively trivial that it sends a harmful message by allowing selective termination.

However, while it is certainly paramount for the state to fulfill its duties of justice, this conclusion still tells us something useful in the meantime. As long as the state fails to fulfill its duties, it has one less reason to allow actions that its failure incentivizes. It should not use its own failure to support people with disabilities as a reason to allow citizens to terminate embryos with disabilities. If and when the state fulfills its duties, however, then the state will no longer send a harmful message by allowing selective termination. This is an intuitive result: when a state displays more concern for people with disabilities, it is less reasonable to infer any harmful messages from its other policies.

Interestingly, however, when the state equalizes opportunities for people with less severe disabilities, the *individual screeners* may then send a harmful message to people with those disabilities. Because of state support, the screeners will no longer have a cost-based motivation to terminate embryos with less severe disabilities. If they continue to do so, then it may be reasonable to see their actions as sending one of the other harmful messages, such as the judgment that a life with a disability is not worth living. As the state displays more concern for people with disabilities, individuals will have to do so as well in order to avoid sending a harmful message.

41 Kageleiry, Samuelson, Duh, et al., "Out-of-Pocket Medical Costs and Third-Party Healthcare Costs for Children with Down Syndrome"; Rafii and Santoro, "Prevalence and Severity of Alzheimer Disease in Individuals with Down Syndrome"; Centers for Disease Control and Prevention, "Life Expectancy."

5. CONCLUSION

I have argued that there is a strong *pro tanto* reason for the government not to allow genetic screening and termination of less severe disabilities (where “less severe” is defined by whether the government can equalize the costs to parents of treatment). The *pro tanto* reason is this: allowing screening sends a harmful message to people with those disabilities that they are not worth the high cost when there is an abled alternative. I have proposed and rejected several considerations that would outweigh the expressivist objection, such as reproductive freedom and cost-based justifications. Nevertheless, there may be other reasons to allow screening and termination that would outweigh the damage of sending a harmful message. I cannot argue against further candidates here, but I will offer a final thought.

When countries like India and China restrict information on an embryo’s sex, they do so presumably because it would cause a sex-ratio imbalance that would detract from the quality of life of a certain number of citizens who would not find partners. As genetic screening becomes more sophisticated, these kinds of countervailing reasons will only become stronger. If information on traits like intelligence, athleticism, and beauty become available before birth, the societal cost of providing this information to parents increases. Among other concerns, we risk losing natural human variation and violating norms of distributive justice. And if distributional concerns can outweigh the value of full information, then it is plausible that concern about a harmful message that conflicts with equal opportunity can also outweigh the value of knowing about a future child’s (less severe) disability. As we think more about the value of genetic information, we may even come to see information as something that detracts from other values, such as those of unconditional love and acceptance.⁴²

Johns Hopkins University and University of Oxford
ajayara2@jhu.edu

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