Notes on “Genetic Ethics” and the Morality of Inclusion
For Philosophy 162
1. The Non-identity Problem
Consider the choice of a deaf woman, who wants a deaf child, to have donor
eggs and sperm screened, and an egg and sperm united and implanted in her
that will produce a deaf child. Is it morally acceptable deliberately to produce a
child with a serious impairment, deafness? The issue is not a deaf child or none:
the woman could have a normal baby, she wants a deaf one.

This case has special features: the woman has a nonmalicious desire to share a
special perspective on the world with her child, and she deliberately acts with the
intention of producing a child with a serious impairment.

Consider more typical scenarios in which a woman who is pregnant has genetic
diagnostic tests performed on the fetus in her uterus. The tests reveal that the
fetus has a genetic defect and that if the pregnancy is brought to term, the child
will have some genetic susceptibility that will eventually result in contracting
some dread disease or suffering some serious impairment. Is it morally wrong to
bring this pregnancy to term rather than to cut it short by abortion? This
question raises the issue of the morality of abortion itself. Setting that important
issue aside, so far as this can be done, one might ask, would it be wrong for a
woman who has no principled opposition to abortion, and who lives in a society
in which abortion is a legally accepted option, to bring this pregnancy to term
rather than to abort it and become pregnant again with what one can assume
will become a normal, healthy baby? (Compare to “Scenario #2: Personal Choice
or Public Health Concern” from the Handout “Challenges of the Genetic Age.”)

The line of thought that answers “Yes, it is morally bad to bring into the world a
child with a serious impairment when one could instead produce a healthy,
normal baby,” prompts an objection from the disability rights advocate. The
objection is that thinking that it is bad to bring a disabled child into he world and
acting on that belief express the view that being born disabled is a bad thing and
hence that it is better that such people do not exist. This attitude cannot coexist
with an attitude that accords equal dignity and respect to all persons including
persons with physical and mental impairments and that strives vigorously to
improve the quality of life of disabled persons. Allen Buchanan explores this line
of thought and possible responses to it in his essay “Genetics and the Morality of
Inclusion.” See the section “Sorting out the Concerns of Disability rights
Activists,” pp. 266-284.

Let’s return to the deaf mother who seeks deaf child case. Suppose in this
scenario a deaf child is born. Suppose as is probable that the prospects of the
child born deaf are not thereby made so bad that the person reasonably would
prefer never to have been born. The person is not so badly off that it would
have been better for him if he had never been born. Still, the deaf child may feel he has a grievance against his mother. He compares his life to the life he would have had if he had not been born deaf and complains to his mother, "I am the victim of wrongful harm, done by you. The lessened life prospects that I face due to being deaf rather than having normal hearing ability are entirely due to your choice.

The deaf child’s complaint is not coherent. He cannot complain that he is made worse off by being born deaf, for in all of the possible worlds in which he is not born deaf, he does not exist at all. Had his mother chosen a healthy sperm and egg that would not have formed a deaf child, the child she would have produced would not have been the very child who now makes the complaint.

The deaf child cannot be harmed by being born deaf, for otherwise he would not have been born. Since he is not harmed by being born deaf, a fortiori he is not wrongfully harmed.

Yet, there is a puzzle. Some of us are inclined to think that at least in some cases of this sort—where a choice is made to produce a child with a serious impairment and the alternative choice could have been made, not to produce a child with a serious impairment but instead to produce a healthy, normal child—the choice to produce the impaired child is wrong.

Consider three cases. In this example, the choice to avoid producing the impaired child does not require having an abortion, so that complication can be set aside.

Case 1. A woman is told by her doctor that she should not become pregnant now, because she has a condition that will bring it about that if she becomes pregnant with this condition, any child that results will be suffer moderate mental retardation. Instead she is prescribed a medicine that she needs to take for a month, in order to prevent this bad outcome. The woman could take the medicine for the required month and get pregnant afterward. But she does not take the medicine, she gets pregnant, and has a child with moderate mental retardation.

Case 2. A woman becomes pregnant and is then told by her doctor that she is suffering from a condition that will produce moderate mental retardation in the child she is now bearing unless she takes a prescribed dose of medicine for a month while she is pregnant. If she takes the medicine, she will bear a child with normal intelligence. She does not take the medicine and she bears a child with moderate mental retardation.

Case 3. A woman has a young child. After taking the child to the doctor for a normal check-up, the doctor informs her that she must give the child a dose of
medicine for a month, or else the child will become moderately mentally retarded. The woman does not give the child the prescribed medication and the child becomes moderately mentally retarded.

Let it be stipulated that in all three cases, the woman has no good reason for behaving as she does.

Many of us are inclined to the view that in these three cases the woman’s conduct is morally wrong and that she is to blame for the mental retardation her child suffers. The woman’s conduct is wrong in each case and wrong for roughly the same reasons.

But this account of the cases cannot be right. Case 1 fundamentally differs from cases 2 and 3. In cases 2 and 3, the child is wrongfully harmed. In case 1, that cannot be so, at least if we stipulate what is virtually certain to be true, that if the mother waits a month to get pregnant she would bear a different child formed from a different sperm and egg combination than would have been formed had she become pregnant before the start of the month. Given that stipulation, the child who is born mentally retarded is non-identical to the child who would have been born if the woman had waited to have a safe conception. (Hence the label “the non-identity problem” is often used for this puzzle.)

What is going on here is that a plausible moral principle blocks us from assimilating cases 1-3 and holding that the negligent woman does wrong in all three cases. The principle is this:

One cannot wrongfully do harm unless one’s act causes some actual person or persons now or in future to be harmed. If your act does not cause some actual person’s condition to be worsened, you cannot be harming the person, and you cannot be wrongfully doing harm.

Another formulation of this idea: You are morally at liberty and should be left free to act as you choose so long as your act does not wrongfully cause harm to some person or persons other than yourself.

The same idea is present in the assertion that we should not acknowledge any victimless crimes. If there is no victim, there is no crime, no wrong done. If no one is wronged, no wrong is done.

The non-identity problem might seem like a cheap verbal trick, but I believe it exposes a deep unresolved problem in our moral thinking. It is not easy to decide how best to frame one’s principles in the light of this problem.
Here are some further examples of the same basic problem at work. Consider reparations for past wrongs such as slavery. As a descendant of slaves, I might reasonably complain that some people today are unjustly enriched by this past wrongdoing, and I am unjustly harmed. Unjust gains and losses have been passed down the generations. But I cannot claim to have been harmed by slavery if the following is true: if slavery had not existed, the pattern of mating in history would have been different, and my mother and father (if they would have existed, more likely they would not have existed) would never have met when they did and produced me. So if slavery had not happened, I would not have existed at all, so I cannot be harmed by slavery or its aftermath.

Consider a choice between two economic policies, Clean and Dirty. Dirty results in significantly higher prosperity for the present generation of people, but harm to the environment that will unavoidably result in toxic harm 200 years from now that will make billions of people’s lives incredibly hellish. Clean is the environmentally friendly policy that results in significantly less prosperity for the present generation of people but no harm to the environment and no toxic waste causing harm of hellish proportions to billions of people 200 years from now. If the choice of Clean or Dirty is a big policy choice that greatly affects how the economy operates, it is plausible to suppose there will be large-scale changes in people’s lives, including who mates with whom, so that none of the billions of people who would live in 200 years if we enact Clean would have lived also if we had enacted Dirty. On this assumption, no one in the future is wronged if we opt for Dirty rather than Clean. Even if what the present generation gains from Dirty is far far less than the well-being difference between the lives the future people would lead under Clean and the lives that would be lived under Dirty, the principle “One should be left free to live as one chooses unless one wrongfully harms others” definitely rules that there is nothing wrong with choosing Dirty.

Notice that the Singer principle, the norm Singer invokes to support his stringent view on what we owe to distant needy strangers, has no trouble coping with the nonidentity problem. The Singer Principle says: If one can prevent something bad from happening, without thereby bringing about anything comparably bad, one ought to prevent the bad from happening. If the woman in case 1 can prevent the bad outcome in which a retarded child exists instead of a nonretarded child without thereby bringing about anything comparably bad, she ought to prevent the bad outcome. The Singer Principle’s conception of bad outcomes is impersonal: we compare the various states of affairs that our choices might bring about, and pick the choice that leads to the best outcome (if doing so would not thereby involve anything comparably bad such as oneself violating some important moral constraint, if such there be). But the Singer Principle, as we have seen in this course, is highly controversial, has implications many of us find deeply counterintuitive. See Singer, “Famine, Affluence, and Morality” and “Outsiders.”
The principle “You are morally at liberty and should be left free to live as you choose so long as you do not wrongfully harm others” has the advantage of preserving options, morally protected discretion to choose as you like within constraints that do not themselves gobble up options. But this principle has implications in the child drowning in shallow pond example that Singer discusses that many of us find hard to accept. The nonidentity puzzle cases are also cases for which the “at liberty” principle yields implications for what is permissible that some find counterintuitive. The Singer Principle avoids these problems but strikes many as too demanding. Can we split the difference between these views somehow, coherently formulate principles that require us to some degree to register the importance of preventing and reducing impersonal bad in our choices but do not eliminate or unduly reduce options?

2. Allen Buchanan on the Morality of Inclusion

In his essay “Genetics and the Morality of Inclusion” Allen Buchanan (and his coauthors Dan Brock, Norman Daniels, and Daniel Wikler) broadly defends the project of using genetic science to improve the human condition from interesting objections by disability rights activists tot he effect that the underlying ethic of the project is incompatible with public policies and a public culture that respect the rights of all persons, eschew discrimination against the disabled, and vigorously protect the rights of disabled persons. He sees the problems as lying with what he calls the “morality of disabled inclusion.” What is that?

Buchanan draws from a train of thought introduced by Daniel Wikler several years ago. He noted that we do not allow mildly mentally retarded people to drive cars on the public highways. We do this for the good of others who might be injured by faulty driving perpetrated by mentally retarded drivers failing to interpret road signs properly and in other ways integrate intelligently the information stream that normal drivers cope with in the course of navigating their vehicles. We also do it for the good of the retarded people, who would be likely to injure themselves if allowed to drive. This sounds reasonable, even noble policy on our part. But notice that the complexity of the task of driving a car on public roads is not a natural fact. It’s a by-product of many choices we make for our convenience. Roads and cars and highway vehicle codes are designed by and large for the benefit of normal average people. They suit us, serve us well, because they were designed to do that. Given the way we have arranged the world, the mildly retarded are pretty much excluded from it. But things could have been otherwise. Maybe to some extent they should be otherwise. We could have designed roads, cars, and motor vehicle codes so that they would have been easier to understand and operate safely. Had we done so, the mildly retarded could have been full participants. Our policies exclude them to marginal status in a world that we have created for the maximal convenience of nonretarded people.
Other examples of similar issues and policy choices are ready to hand. Until recently, roads and sidewalks and stairs in public and private buildings were negotiable easily by the people with two good legs but not by the lame and the legless and the blind. Again, we construct a social world that is wonderfully convenient for the able. The price is marginal status and maximal inconvenience for the less able and the nonable.

Buchanan’s take on this is what he calls the morality of inclusion. He says that theorists have framed the issue of justice as how to divide fairly the fruits of social cooperation, but a prior, more fundamental question is how to set up the framework for social cooperation. How we set up the dominant cooperative framework in our society determines who will be disabled and who will be able. (Buchanan distinguishes physical or mental impairment, i.e. “impairment of some aspect of normal functioning for our species” (p. 285) from disability. Buchanan, p. 286: “to have a disability is to be unable to perform some significant range of tasks or functions that individuals in someone’s reference group (e.g., adults) are ordinarily able to do, at least under favorable conditions, where the inability is not due to simple and corrigible ignorance or to a lack of the tools or means ordinarily available for performing such tasks or functions.” Having the impairment of nearsightedness, for example, may not be a disability in modern societies, where eyeglasses are readily available and anyway the need for acute vision for most people is not of crucial import. In a hunter gatherer culture, where eyeglasses are not available and keen eyesight is a prerequisite for being a successful hunter, nearsightedness may be a grave disability.

The dominant cooperative framework idea is explained on pp. 288-289. Roughly, the dominant cooperative framework is the way basic practices and institutions are structured, in terms of the skill and stamina and other personal traits required to be a regular participant in them. Literacy, facility in the use of language, and the ability to manipulate at least elementary mathematical and other symbols are such requirements in modern industrial society.

Buchanan explains his idea of the morality of inclusion on p. 258: “At the deepest level, a theory of the morality of inclusion would articulate criteria for membership in what might be called the primary moral community, specifying the characteristics that individuals must have in order to qualify as worthy of equal consideration and respect. Such a theory would also delineate the scope and limits of our obligations to include other individuals or groups in various mutually beneficial cooperative arrangements and hence make them eligible not only for the concrete benefits of participation in those arrangements but for the status of equality that is accorded to those who stand in relations of reciprocity with one another.” The theory that Buchanan envisions would presumably tell us that nonhuman primates and other animals are not in the primary moral community and human persons are, and would stipulate what qualifies one as a
person. The theory then goes on to say to what extent we owe it to all members of the primary moral community that the dominant cooperative framework be set so that they can be full participants.

Buchanan does not try to develop such a theory. He does identify two legitimate moral interests that people have with respect to their dominant cooperative framework (DCF). One is the interest in not being disabled, in the DCF being set so that one can participate fully in it. The other interest is that the DCF be set so that it is the maximally “productive and rewarding form of interaction in which he or she can participate effectively” (p. 293). Justice requires that these interests somehow be appropriately balanced. Buchanan then argues that various arguments put forth by disability rights activists if taken literally ignore altogether the legitimacy of the second interest and proceed as though inclusion were the only aim of justice in this area.

[COMMENT. Buchanan’s discussion is interesting but I wonder how useful is the framework he offers us for thinking through the moral issues that concern him.

First, it is not true that existing moral approaches are perplexed by the issue of how and to what degree to include variously able people in social cooperation. Utilitarianism says we should choose policies and acts to maximize human well-being. This tells us how to balance conflicting interests of people. We may worry that we cannot even in principle get a measuring rod for human well-being, but to the extent that commensurability is only partial, utilitarianism tells us that we should pick some policy that is as good as any other so far as our best measurements specify. Prioritarianism modifies utilitarianism by holding that we should maximize a function of well-being that gives greater weight to obtaining a gain for a person, the worse off the person is. (This is a broad family of views; you get a specific basic moral principle by specifying the priority weighting.) A Lockean rights theory tells us we have the moral right to live as we choose provided we do not harm others in specified ways that violate their rights against physical assault, fraud, theft, physical damage to person or property, or extortion. We might also mix and match these views, for example, by asserting utilitarianism or prioritarianism constrained by certain basic rights, or by adding to Lockeanism the rule that we owe everyone access to a decent minimum of resources. Any of these familiar views combined with the relevant facts yields directives on the problem of inclusion of variously able people in social cooperation.

Any moral view that assigns fundamental status to person needs to tell us what qualifies as a person. To this extent the morality of inclusion is surely right. But I don’t yet see why this issue must lead us to identify choosing a dominant cooperative framework as a key moral imperative and one that is central for determining the rights of disabled and partially able persons.
For Lockeans, the structure of Lockean rights automatically sets the terms for fair social cooperation. For consequentialists, the issue is how to tinker with existing institutions and practices (or conceivably in some cases radically transform them) so they induce the best long-term outcomes.

Why think the central question for determining whether society is fair to the disabled is the character of the DCF? Whatever exactly the dominant framework is, surely what matters is what treatment the disabled get, whether from the dominant or non-dominant part of the framework. The specific practices dealing with the disabled should be the focus. For a severely mentally ill, retarded, or physically incapacitated person, what matters is not so much the entry requirements for jobs and whether one is allowed to vote in elections, but the answers to questions such as: Do I have adequate access to basic resources? Do the social rules impinging on me appropriately balance my interest in personal liberty and my need to be protected from self-harm? Am I in contact with relatives and friends who have personal affection for me? Am I treated with friendly civility and respect by state officials, sellers of goods and services, and others with whom I interact?

For people who are mildly incapacitated or at the margins of disability, their chief reasonable concern will often not be whether they have fair access to employment, but whether they have the option of retiring honorably from work and career and relying on a disability pension of some sort. For most people, paid work (or paying self-employment) is a necessity of life, not a privilege or benefit, and one the performance of which becomes increasingly onerous as ailments due to advancing age, accident, disease, or aggravation of congenital maladies worsen. What benefits a decent society should offer to the range of people who fit this description is a hard question that needs to be squarely confronted.

Buchanan in my view concedes too much ground to the idea that the problem of what society owes to people with disabilities is essentially a civil rights issue. On this view, those with impairments are subject to prejudice and wrongful discrimination, just as women, members of racial minorities, and people with nonstandard sexual orientation face. If the problem is prejudice and wrongful discrimination, the remedy broadly speaking is a set of laws and cooperating culture that enable people to compete with others for social advantage on equal terms. This is an aspect of the problem people with disabilities face. Think of a qualified woman lawyer who is unable to walk and hence cannot gain access to law offices and courts unless ramps are provided, or a blind person who cannot walk along roads supported by taxes paid by all unless traffic crossing signals are set to be detectable by auditory or tactile means. An employer hiring for a position might assume incorrectly that a paraplegic applicant obviously could not
do the work she is in fact well qualified to perform. But this is not the core problem that must be solved to determine fair treatment for people with disabilities. The main issue surely is what do able and better off people owe by way of support to enhance the quality of life of people who suffer from handicaps that make it unusually difficult or unfeasible for them to meet their needs by their own unaided efforts.

Framing the problem of fair treatment for those with disabilities as one of discrimination and denial of civil liberties encourages thinking in Buchanan’s terms, according to which, the core issue is to determine how to set the DCF so it does not unfairly exclude anyone from full participation. I have suggested the issue of exclusion is one aspect of the problem, not the whole of it or even the major part. Here is a formulation: How to set terms of social cooperation so that the benefits and burdens of social cooperation under those terms are fairly shared among all affected people. Excluding someone from the requirement to work (or for that matter to shop for oneself in stores) can be oppressive, but so too can requiring a very unable person to work (or shop) in order to meet her basic needs. Other things being equal, providing a benefit to a person or lifting a burden from her is always desirable (and opportunities to contribute in various ways are important benefits), but we must always weigh the gain to the person against the cost to others. Different moral theories uphold competing ways of doing these cost-benefit comparisons; choice among such theories is hard.

One might seek further light on the problem of what is owed to people with disabilities by checking to see how the approaches to social welfare policy outlined by David Schmidtz and Robert Goodin would deal with this issue.

The criticisms of Buchanan’s approach suggested in this comment do not necessarily imply any criticism of Buchanan’s responses to the objections of those he calls disability rights activists against the project of using advances in genetic science to improve the human condition.

One issue explored by Buchanan under this heading is especially interesting. Consider this generic objection against a proposed social policy: The policy is wrong because it conveys or expresses a message that is either inherently and or will lead to bad consequences. How should one respond to this expressivist objection?

One might say that if a proposed social policy is supported by the balance of moral reasons, then the message it expresses is just that—we are implementing this policy because it is right, because it is the one best supported by moral reasons all things considered. So construed, the expressivist objection never provides an independent reason to choose this or that policy. It just directs us to select the best one.
This response supposes that what a policy expresses or symbolizes is what a perfectly reasonable and well informed person contemplating the policy would take it to be expressing or symbolizing. This supposition is too simple. What message a policy would express to a perfectly reasonable and well informed observer is an important consideration, which takes us back to the imperative of looking for the best policy. But actual people affected by a policy may not be perfectly reasonable and well informed. What then? What the policy if instituted would symbolize to actual people warts and all is a relevant consideration for choice of policy. We might think, we should always choose the independently best policy and add to that a policy of promulgating the correct rationale and relevant information to show people what it expresses, properly understood. But people’s resistance to correct interpretation of policy may be deep, perhaps intractable. In this case, the actual impact of a policy, given what it would actually express to people, is a relevant consideration for policy choice.

To take a simple and fanciful example, suppose nutrition scientists make the surprising discovery that plain white bread is the best food for you. The government plans a campaign boosting the merits of white bread, placing it in public school lunchrooms, etc., but learns that white racists are empowered by news of this impending campaign. The white racists are saying “We were right all along--White is better! White power!”. In vain the government tries to provide correct information to prevent people getting the wrong message, but the white racists are numerous and impervious to facts and logic. In this case, I am prepared to allow that the bad symbolic effect of the campaign to boost people’s health by touting white bread might lead a good government to drop the campaign. But this is a far-fetched case. Surely in most real-life circumstances the better course would be to stand fast by the sensible policy and provide people the information and policy rationales that will prevent them from drawing wrong inferences about the expressive meaning of the policy.