

**We
need
to
talk
about
this**

About the new eugenics. Third edition.

Angelina Souren

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Third edition
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**We need to talk
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by

ANGELINA SOUREN

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“Life is not worth living if I cannot have pasta or bread again.”

– Monica Seles

7. Lives not worth living

I wanted to know whether it was possible to come up with a universally applicable guideline for the new eugenics that respects diversity and prevents harm as much as possible. Such a guideline would have to be amended eventually, but we need a course and a compass that we can use right now.

To create generally applicable regulations that don't collapse at the first legal challenge, we first need to come up with generally applicable definitions. Within the context of consumer eugenics (tinkering with our offspring, germline modifications), we must act primarily in the interest of the child and we must prevent any harm to the child (and that includes the resulting adult).

But what constitutes harm within this context?

First of all, we have this principle:

Allowing someone to be created does not harm that person.

This is a generally accepted view that I agree with, even though there are groups of people who believe that it is wrong to have children, for various reasons.

But if I accept that for example a hearing child and a deaf child are equally valuable, I run into the problem that if a hearing child is injured in such a way that the child loses his or her hearing, we would do consider that harm. This also applies for adults and the laws in most countries agree with this view too. Companies ensure the safety of their employees, for example, for that reason.

That forces me to ask myself whether it constitutes harm to allow a child to be born without hearing (or to be born with a condition that will eventually render it deaf).

If I explore that, then the following becomes clear:

We consider it harm when someone else changes us against our wishes, particularly with regard to physical changes.

We seem to be less clear on psychological changes, and that is because they are much harder to identify and quantify. We don't start lawsuits

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against bad schools and bad teachers when they have changed our children in a way that good schools and good teachers don't – even though the former can also mar a child for life. To a large degree, we still rely on the presence of a physical component to consider something harmful enough.

We don't generally think that a surgeon harms a person if that person decides to undergo cosmetic surgery for purely aesthetic reasons, but would consider it harm if this were to happen against the person's wishes. (There can of course also be harm if the surgeon is professionally negligent in the sense of using the wrong sutures or other errors, but that is not the context we're talking about here.)

So the crux appears to be this:

We should not change another person (physically) if that change isn't that person's explicit wish.

(The right to integrity of the body also plays a role here.)

A child who doesn't exist yet can neither express nor have wishes yet, which is why then have to make the following decision:

We should assume that any change we would carry out to that child is not based on that child's wishes but against its wishes.

That is a potentially problematic conclusion.

Should this then also for example include PGD, as PGD itself can do damage? No, because actions to detect and identify conditions or diseases are excluded from what constitutes harm, as they are – or should be – applied to prevent harm, for example, to make it possible to treat a baby from birth as opposed to letting the parents take the baby home, only to have it diagnosed later with a condition that could have been treated from the start, which might have prevented a lot of pain. Techniques like PGD would also help detect conditions that lead to lives not worth living (which I also still need to define, but I'll come to that).

On the other hand, genetic changes accomplished by techniques such as CRISPR should be included (that is, considered harm), unless they are done to enable lives that would otherwise not be possible and/or treat developing health problems.

(Remember that we are looking for a guideline that we can use right now.

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Such a guideline can and very likely will have to be adapted later. By then, we will have a lot more experience with technologies like CRISPR and we'll have gained a lot more insight.)

Generally speaking, however, we also have to take this into account:

Until a child reaches majority, the parents are required to make decisions for the child and in the child's best interest.

Is there a potential conflict here, between not doing something against someone else's wishes, the inability of the very young to develop and express wishes of their own and the parents needing to act on their behalf? I clearly need to explore this further.

It is acceptable to most people – though not everyone, mostly on religious grounds – that parents ensure that medical intervention takes place when this is required to save a child's life. If a healthy child contracts a disease or suffers an injury that without medical intervention would result in a so-called diminishment (or death), the latter also clearly counts as a change that would take place against the child's wishes whereas the medical treatment would be according to its wishes. No child wants to have appendicitis, for example, and not be treated for it and it is also very unlikely that a hearing or seeing child would genuinely want to be deaf or blind. So there is no conflict here.

Yes, a child that wants its ears pierced may ask for this as a result of peer pressure, but it is still a wish that comes from the child. It is akin to an adult asking for cosmetic surgery for purely aesthetic reasons. That too is the result of some form of societal pressure. No one should force a child to have its ears pierced; that would be harm. Also, a parent can stop a child from having his or her ears pierced on the basis of the argument that the child (minor) is too young to be able to make such decisions and the procedure is no medical necessity. There is no conflict here either.

So it looks like this definition of harm holds up and would not get in the way of parental duties to existing children (children that are alive, as opposed to children who do not exist yet).

Changes implemented not explicitly according to our wishes must be seen as occurring against our wishes, and constitute harm. (Note that this would also apply to male circumcision and female genital mutilation.)

So, in principle, any changes carried out to a child who doesn't exist yet must be assumed to be against that child's explicit

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wishes, hence constitute harm, unless that change would enable a life that would otherwise either not be worth living or not even possible.

Now I have a basis that I can work with.

I now also can say the following (but keep in mind that I still need to define what a life not worth living is).

We cause harm if we create a child who will have a life not worth living if we are able to prevent that.

However, a child born into such a life without the parents' prior awareness that the child would have that kind of life is not harmed by the parents because the parents weren't in a position to prevent this life on the basis of the knowledge they had. (This is important.)

Note that this definition also implies that if we become able to remedy the situation, for example through the use of CRISPR, we should.

But what is a life not worth living?

Most people probably see "a life not worth living" in terms of physical pain and of the increasingly terrible suffering that will only lead to the child's death. The parents and other persons in the child's surroundings may gain something from the experience and possibly become more compassionate as a result, but the child gains absolutely nothing from the experience. On the contrary, it only suffers.

At this point in history, it is not possible to say how much pain the child suffers, or whether it is even aware of the pain. We don't know.

We can't leave "a life not worth living" undefined, however. It would leave the door open for people acting on the basis of personal opinions or feelings that have little to do with the resulting child's welfare. It could also mean that every case would have to be looked at individually, which would soon cease to be practical. So we need a definition that we can apply to every case, in principle.

I need a basis for defining what makes a life worth living.

For that, I use the following principle:

Every human being has the right to a life in dignity.

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This is the so-called principle of humanity. (See the 2003 working paper by Buchanan-Smith or the course “Humanitarian response to conflict and disaster” by the Harvard Humanitarian Initiative and Harvard Center for Health and Human Rights.)

We probably agree on this principle of humanity worldwide, no matter where we are from or what our religious background is. So this can offer the first step toward a definition of “a life not worth living”.

But...

What is dignity?

As it turns out, it is not possible to decide what constitutes dignity for someone else. We can only define it for ourselves. Consider that nudity equals a lack of dignity for many people, but not at all for many other people. Being too ill to eat and use the bathroom without assistance can constitute an unbearable lack of dignity for one person but be acceptable to someone else. Being unable to breathe and needing a ventilator may be where the latter person draws the line, while someone else may still find that acceptable but would, on the other hand, like to avoid being in a coma or some other form of vegetative state for, say, more than a month.

These physical forms of loss of dignity are not the only ones imaginable. Alzheimer’s, for example, can cause a loss of dignity too, even though it has its basis in physical developments in the brain. Almost all of us would likely want to avoid getting Alzheimer’s disease. However, one reason for excessive alcohol consumption is the loss of awareness it results in and you can probably see drunkenness as akin to temporary Alzheimer’s. Just like we can adapt to natural physical changes, we could also decide now that we would accept natural changes to our future selves, such as Alzheimer’s, and would adjust our expectations accordingly. The person who you are today may not be the person who you will be twenty years from now. But I digress.

Dignity clearly is a personal concept. It is the result of cultural and religious influences and one’s personal preferences and experiences.

The examples I just gave, of being on a ventilator and so on, are western and contemporary, but that does not matter. The principle of dignity itself, however, will very likely hold for a long time, even if our views change of what is acceptable and what not.

This takes me to the next step:

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To be able to decide whether we are living a life in dignity or not, we have to be able to make decisions.

So now we have the following:

- To allow a human being to come into the world does not constitute harm to that human being.
- To allow a human being to come into the world constitutes harm if that human being will have a life not worth living, if this was known in advance and if it was possible to prevent that.
- To implement physical changes (including genetic changes) against a person's explicit wishes constitutes harm.
- As unborn children are not yet able to express wishes, any changes (including genetic changes) carried out to unborn children must be seen as being against the explicit wishes of those children, with the exception of a change that would enable the child to come into the world (meaning that without the change, the pre-embryo or embryo would not be viable) or heal the way we would also try to heal appendicitis or a heart problem.
- All humans have a right to a life with dignity (the principle of humanity).
- It is not possible to define dignity for another person.
- To be able to decide whether a person has a life with dignity, that person has to be able to make decisions, with or without explicit assistance.
- A person gains the right to make his or her own decisions at majority (full age, coming of age). In many countries, this is the age of 18 years. This is therefore a logical age to attach to this guideline (and attaching a fixed age limit to my non-discrimination guideline for embryos helps rule out arbitrariness).

The above leads to a workable definition of "a life not worth living":

A life not worth living is a life that has at least a 95% probability of not making it to the age of 18 or that has at least a 95% probability of the person not being able to make his or

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her own decisions at that age, even with assistance.

I feel that it is necessary to point out that this does not represent my personal preference. I balk against the idea of declaring that someone who passes away at age 4 or 9 or 15 does not have a life worth living. I came up with this definition because it seems to work very well in practice and that means that it contains little risk of arbitrariness or corruption. This definition also does appear to diminish harm as much as possible while not promoting discrimination or prejudice, hence respecting diversity.

It holds up for severe psychopathy as well. If a gene, allele or genetic combination is identified that predicts a 95% likelihood that someone will engage in arson, torture of animals and so on without there being a cure or treatment to prevent this from happening, then such persons would also fall within the category of persons who are unable to make their own decisions at the age of majority. They would make their decisions on the basis of harm to others and seek to harm, instead of avoiding it. This means that such a person would have a life not worth living, clearly also for his or her own sake. This would likely only pertain to rare cases, in practice.

The ability to make decisions is useless without being able to communicate them. Appropriate assistance should be able to achieve that communication, if needed, and we have to be diligent in this respect. Persons who require assistance with the actual decision-making should have that assistance. Most of us enjoy some kind of assistance in our decision-making, regardless of whether we are aware of it.

Identity, legal persons and rights

Some bioethicists strongly object to the treatment of pre-embryos and embryos (as well as fetuses) as if they aren't humans. When does a person begin and when do his or her rights begin? Within the context of liability of the parents in cases of intentional "diminishment" (selection of pre-embryos with a certain trait such as deafness), some scholars have mentioned identity. That raises very complicated questions for which there are no answers. At what point can we say that we have changed someone's identity? At what point does someone's identity begin? Nobody knows. Identity is partly, and maybe even mostly, formed after birth, and so that discussion only seems to lead further astray instead of providing more clarity.

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But both that approach and mine run into the same problem: Can someone who does not exist yet – a pre-embryo or even a not yet existing embryo – be seen as a person, and therefore be assigned rights?

If not, then how can there be harm if, for example, we were to carry out genetic changes to an embryo, under the assumption that this would be against the future child's wishes? (I mean this within the context of the law, not morally speaking.) If yes, then how can we legally allow any form of abortion of embryos of up to 24 weeks and not consider it murder?

So we seem to have a need for a new international category of legal personality. If a business can be a person and a river and a mountain in New Zealand can be legal persons, then surely it is also possible to have a separate category of legal personality for pre-embryos and embryos or fetuses up to 24 weeks. (An embryo is generally considered a fetus when it is at least 10 weeks old, so I understand, but in this book, I have mostly used the currently often used time limit of 24 weeks, the point up to which abortion is commonly allowed, although this point is not set in stone.)

Cell clusters in those stages would not have a legal right to life yet (so this would therefore not clash with existing abortion rights), but they should have the right not be discriminated against on the basis of the characteristics of the eventually resulting person (child) unless those characteristics would give the child a life not worth living. This safeguards basic human rights concepts like respect and dignity as well as the principle of unconditional love as the basis for good parenthood and inclusive solidarity in society.

This may be a stretch for many and take some getting used to.

For the time being, such cell clusters should also have the right not be interfered with in a way that would constitute harm if similar actions were carried out on a newborn. We wouldn't want to apply CRISPR to a newborn so that its eye color would match the home furnishings better, so we shouldn't do it to gametes or pre-embryos either.

A pre-embryo that does not yet exist, of course, does not have any rights and cannot be harmed. You could perceive sperm and egg selection on the basis of their characteristics as a human rights violation, but the problem with that is that a human who never comes into existence

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doesn't have any rights. Here too, however, we can apply the principle of non-discrimination to sperm and egg selection. Sperm and egg selection should take place "blindfolded" (which is what I also argue for abortion). Lives not worth living should be the only exceptions and conditions such as genetic deafness or dwarfism do not fall into that category of lives not worth living.