

**We
need
to
talk
about
this**

About the new eugenics. Third edition.

Angelina Souren

**We need to talk
about this**

We need to talk about this
Third edition
Copyright © 2017-2020 Angelina Souren
All rights reserved.

Essay, non-fiction.
Publisher: SmarterScience, Portsmouth, England, U.K.
Simultaneously published as e-book.
Amazon paperback edition, 5.5" x 8.5", glossy cover.
Printed on white paper in ChunkFive Roman, Britannic Bold and Bookman Old Style.
ISBN: 9781692436414

Version date: 28 June 2020

Keywords: bioethics, eugenics, assisted human reproduction, diversity, discrimination, equality, disabilities, inclusion, health, future societies

Thank you for having purchased this book. You can quote small passages from this work (up to three paragraphs), as long as you also list the source of the quotation. You are not allowed to republish (larger parts of) this book without prior written permission from the author (angelinasouren@gmail.com). Thank you for respecting this, for recognizing that a lot of hard work went into this book.

**We need to talk
about this**

by

ANGELINA SOUREN

About the new eugenics.

Third edition.

Table of contents

0. Foreword	i
1. A provocative introduction	1
2. Utilitarian reasoning	5
3. Eugenics, old and new	19
4. Why we need to talk about this	25
5. Bias	37
6. Brain-based conditions	43
7. Lives not worth living	61
Identity, legal persons and rights	67
8. A guideline for the new eugenics	71
An exercise	74
Implications for wrongful conception, wrongful birth and wrongful life cases	76
9. The bioethical imperative	87
10. Consequences	93
11. Lessons from the past and present (appendices)	101
12. Afterword	139
13. Sources of information	143
Articles in newspapers, magazines and on blogs	143
Books and book chapters	157
Courses	158
Scholarly articles and reports	160
Videos	167
About the author	(171)

“I know we can't abolish prejudice through laws, but we can set up guidelines for our actions by legislation.”

– Belva Lockwood

8. A guideline for the new eugenics

As discussed in earlier chapters of this book, enhancing or designing our offspring does not provide guarantees for our offspring's wellbeing or even competitiveness at this point (with the limited knowledge that we currently have).

And as I have also made clear in the previous chapters, I believe that for the time being, we should restrict ourselves, for the following reasons.

- At this point, we are unable to predict the effects of allowing an unbridled practice of personal or mandatory eugenics on the human species. We have made many mistakes in the past when we blindly applied what we thought of as technological advances without being able to see their future deleterious effects.
- Perceived impairments are often hindrances created by society.
- Human variations that some people may currently think of as less valuable (less competitive or less worth having around) may become much more valuable in the future. We can't assess what we don't know yet.
- There is a potential for harm to the resulting child if the child does not meet its parents' expectations, for whatever reasons.

Here is what I propose for the practice of the new eugenics, for the time being:

Only allow selection that selects against children who have at least a 95% probability of not making it to their 18th birthday or who have at least a 95% probability of not being able to make their own decisions at that age, with or without assistance.

I am aware that some countries already have an accepted practice that goes beyond what I propose.

The medical profession can give us the statistical probabilities for

whether or not a child will be able to make its own decisions at the age of 18 (age of majority, coming of age), given it has a certain genetic condition. There is no such thing as 100% certainty in most of these cases. All we need is a good enough certainty, something that we can work with (also in the courts). We can work this out in such a way that we don't need to be concerned about the validity of the statistics (bias). We could, for example, ask all countries to supply their individual assessments and use the average.

Gut feelings against this type of reasoning can be very strong, such as the impression that this way of thinking diminishes the value of some lives, no matter how short. I have those feelings too. This is not necessarily a problem, however. Parents who feel very strongly about this are unlikely to select against such a baby and are also highly unlikely to sue a state to get what they want. The courts only need to know how to deal with cases that are brought before them. Cases that do not show up in the courts solve themselves.

I also have some doubts about how people will determine whether someone can make his or her own decisions. If you consider that for a very long time, we've thought that other animals had no cognitive abilities and were not able to feel emotions, hence were not able to make conscious decisions either...

At this point, I don't think we should criminalize the decision to accept a life, but this may of course change in the future. By that, I mean that we may have to decide that an embryo or pre-embryo that will result in a baby with Lesch-Nyhan syndrome must not be implanted and that embryos or fetuses that test positive for such conditions must be aborted.

Thus, the implantation of for example an embryo that would lead to genetic deafness would be allowed and would not be a condition that we would test for as a basis for deselection. I think we should carry out much more extensive tests at birth (many of which we currently don't do yet, also for certain infections) so that we can treat children from birth and not, for example, be forced to diagnose them at 1, 2 or 5 years old when a lack of a certain protein has already done a lot of damage to the child's body (and mind). Testing at birth including brain imaging, if possible, should also be carried out for personality disorders and other conditions that are considered to be of a mental nature, and then followed up by the provision of support just like we also support persons with physical conditions. Brain scans would also detect irregularities such as neuroblastomas.

If the regulations state that discriminatory selection of eggs, sperm and

pre-embryos is not allowed unless it would prevent a life not worth living as I have defined here, we would have a great deal more clarity than we seem to have now.

The principle of what constitutes a life not worth living as I have defined it here seems to hold up well in practice. Some examples are Tay-Sachs disease, Lesch-Nyhan syndrome, Leigh syndrome, types of severe combined immunodeficiency (SCID) and (some cases of) mitochondrial DNA depletion syndrome. (Keep in mind that this should also go hand in hand with applying techniques like CRISPR first to enable these lives and remedy lives not worth living.)

From what I've written in this booklet, it automatically follows that mitochondrial replacement therapy (MRT) – colloquially known as the creation of three-parent babies – should be allowed (technical and practical issues aside) because it would enable the creation of lives that wouldn't be possible without MRT. (I feel that it is not my place to tell a family unable to create offspring without ART to adopt an orphan.) This may change in the future, possibly leading to more snowbabies. As we cannot possibly know the long-term effects of the application of such techniques, MRT should only be used as a last resort. Britain and Mexico are examples of countries that allow the clinical application of MRT.

I am not saying that this guideline should always remain in place. A common response to the previous two versions of this book was that people let me know “I don't agree with you” without specifying what they meant, and I suspect it had to do with this guideline. I am not saying that we need to keep proceeding this way, but that we should do this for the time being. It would allow us to gain more knowledge and, very importantly, limit any harm that we do while we explore the applicability of technologies like CRISPR. Once we have enough experience, we can slowly take it forward.

Future societies will be different, just like I grew up without mobile phone and tablet while many of today's children have at least a mobile phone. Whatever I prefer personally should play no role. What is good for the human species should play a role (and this has to include concern for other species; see also Chapter 9). I do not think that relocating to Mars is a good option if we don't take the time to learn and be able to apply the lessons that we are taught on this planet. We can't keep wrecking planets and moving to different planets endlessly.

An exercise

To get an idea of the current practice, let's take a look at what the U.K.'s Human Fertilisation and Embryology Authority (HFEA) does. It uses a growing list that currently contains about 400 conditions that pre-embryos can be tested against, but this means that couples must use IVF. In 2005, the HFEA issued the consultation "Choices & Boundaries: Should people be able to select embryos free from an inherited susceptibility to cancer?" "We want to hear the views of patients, carers and representatives of affected families, staff in treatment centres, disability groups, parliamentarians, academics and the wider public about the use of PGD for these types of conditions," the Chair of HFEA stated in the introduction. That consultation contained the following questions (see hereafter). If you didn't take part in it, how would you have answered these questions? Do you think that embryos who have a high breast cancer probability should not be allowed to develop into babies and grow into adults? Why, or why not? Do we have the right to withhold life from such an embryo? What about the embryo that would be allowed to be born instead if the embryo with the high breast cancer chance is discarded? Should that embryo be given to other parents, perhaps? In December 2017, a few days before Christmas, an American woman gave birth to a baby whose embryo was frozen in 1992. She felt that that baby would be as good as any other baby, even though it is not genetically related to her. (Such children are called snowbabies.)

- **Question 1:** We are interested to find out how you feel about using PGD to test for lower penetrance conditions such as inherited breast cancer. To help put your views about this in context, it is important to understand how you feel about PGD for fully penetrant conditions such as cystic fibrosis or haemophilia. Do you agree with the use of PGD in general. For example, for fully penetrant conditions that are present in the child?
- **Question 2:** The HFEA guidance to PGD centres states that PGD should only be available where there is significant risk of a serious genetic condition. Given the lower penetrance, later age of onset and potential treatability of inherited cancer conditions, do you consider them to be serious genetic conditions?
- **Question 3:** The HFEA guidance to PGD centres states that PGD should only be available where there is significant risk of a serious genetic condition. Does the penetrance of the condition affect whether or not you consider it to confer a significant risk? In your opinion what would be the lowest penetrance – in percentage terms – that would confer significant risk?
- **Question 4:** The HFEA guidance to PGD centres states that the

views of the people seeking treatment should be taken into account when considering whether to offer PGD. There needs to be a balance between the views of those people who would seek to use PGD to avoid passing on a condition and the views of wider society that may have ethical concerns about them doing so. In your opinion, how much emphasis should be placed on the views of those people seeking treatment?

- **Question 5:** The HFEA guidance to PGD centres states that the use of PGD should be consistent with current practice in prenatal diagnosis. Do you agree, with respect to lower-penetrance conditions, that the availability of PGD should be determined by current practice in prenatal diagnosis?
- **Question 6:** The HFEA wants to know where you feel the boundaries for the use of PGD lie. Considering penetrance, age of onset and treatability, what type of condition do you think should never be tested for in embryos using PGD?

The Scottish Council on Human Bioethics spoke out very clearly. Among other things, it said the following:

“Given that many respected organisations, and various national legislations, consider the early embryo to be due full protection as a human being, the SCHB regrets that U.K. legislation regards the early embryo as so readily dispensable.”

It also wrote:

“the practice of PGD is fundamentally flawed as it fails to recognise the true nature of, and hence undervalues, human embryos. Following the creation of the embryo, when the genetic composition of the individual is determined, the development of this embryo is a continuous process right through to adulthood. Any attempt to demarcate a point in this process, before which an embryo should be considered a person, is arbitrary. In the absence of clear evidence to the contrary, the precautionary principle dictates that even the earliest embryo should be accorded full protection as a human being.”

On 21 January 2013, HFEA responded to the question of whether HFEA had, prior to 2008, received a PGD application to select in favor of a disability. The answer was negative (F-2013-00009 - PGD applications in favour of disability).

I believe that the advent of artificial wombs (uteruses) will provide a way out of the dilemma that currently still pitches so many people and institutions against each other based on the opposing views they have

on the rights of embryos. When abortion ceases to be required or desirable in certain circumstances as offspring are created in labs and grown in artificial wombs, procreation becomes a chosen and parenting perhaps an assigned privilege, today's reasons to discard embryos will have disappeared. It will be possible much sooner before it will become mainstream, however. On Twitter, Hank Greely (Stanford) said that it will likely take 50 to 100 years. I think it may begin to happen sooner.

Implications for wrongful conception, wrongful birth and wrongful life cases

Three kinds of lawsuits are particularly relevant for what I propose. Wrongful conception and pregnancy, wrongful birth, and wrongful life cases are currently all based on the idea of negligence on the part of labs, hospitals or medical professionals.

Wrongful pregnancy or wrongful conception cases imply that the parents who bring such a case didn't want a child. Any child. Think of unsuccessful voluntary sterilization as an example. This does not clash with what I propose. There is no element of discrimination here.

Wrongful birth cases are lawsuits by parents who have had a child with a significant disability or impairment. These cases can have an element of discrimination. These are cases against, for example, doctors who should have informed the parents about a medical condition in the (pre)embryo or fetus, the parents claiming that in that event, they would have opted for abortion. Usually, the parents claim damages due to psychological upset and financial damages related to extra costs involved in caring for the child. In practice, these claims usually contain an element of medical malpractice (negligence), an element of the need to find financing for a child's care or both.

As Ronen Perry pointed out in his 2008 paper, in these cases (as well as in wrongful life claims), the medical professionals (or labs) involved tended to have provided reassurances, rather than having for example amputated the wrong leg or, as happened in Britain recently, having amputated breasts that did not need to be removed. Of course, one of the problems medical professionals face is that the public wants to receive a 100% guarantee from them, which is impossible. That, however, usually isn't at the heart of the matter here. Rather than having provided reassurances too lavishly, labs or medical professionals tend to have messed up in these cases (mixed up samples, sent the wrong results, omitted to do a test or carried out a test incorrectly, etc). It is understandable that parents may end up feeling badly wronged, and

it is also understandable that parents seek redress through the courts rather than through the medical regulatory authorities. However, there is also always the question of how these parents would have responded if the condition of their child had been the result of a traffic accident or a fall down the stairs at the age of 1.

In 2014, Mpaate Owagage published a clear analysis of the developments around wrongful life cases. “A wrongful life claim”, he wrote, “is one brought for or on behalf of a usually extremely disabled plaintiff who claims recompense on the basis that but for the defendant’s negligence, they would not have existed at all.” When courts do award damages, these cases essentially become wrongful birth cases, except that the damages are awarded to the claimant (plaintiff) and not to the claimant’s parent(s), thereby essentially safeguarding the claimant’s care. Ivo Giesen analyzed the ins and outs in an article published in 2012 and held that “most notably the cultural background and/or the legal policy reasons within a certain tort law/medical liability law system” decide the issue in practice.

Wrongful life cases are problematic. They are started by or on behalf of a child or resulting adult. They tend to hinge on three factors. The first one is the question of whether the defendant had a duty of care toward the claimant. If so, the second question is whether this duty has been breached by the defendant and, third, whether this resulted in demonstrable damages for the claimant (for which damages may be awarded).

There are two different types of wrongful life cases, as well as two different legal approaches (see article by Owagage), but these two do not fully overlap. The difference in the cases rests on the principle of harm as I have identified it in this book, namely the occurrence of a physical change that can easily be assumed to occur against a person’s will.

In cases in which the child has for example Tay-Sachs disease or any other genetic condition, the child has this condition irrespective of what a physician, hospital or lab did. Nobody caused this condition. The condition is not the result of an action (other than the creation of the zygote from which the child developed). (This will change in the future when a duty may develop to carry out techniques like CRISPR on such an embryo, but it will change in the opposite way.) So it cannot be said that the defendant caused any damage to the claimant. This becomes muddled when we consider the creation of a zygote in the lab, but in that case, why not sue the parents too, as they are primarily responsible for the child’s existence? But even for such cases, the world seems to be growing toward the consensus that to be alive does not constitute damage in itself.

In cases in which the child's mother for example had rubella during early pregnancy, however, physical changes did occur. These changes would not have occurred if rubella had not been present. At first, this seems significant, but in these cases too, all logic leads back to one overriding question, namely whether the child would have been better off if it had not existed. This could have allowed a different child to exist that would not have been affected by, for example, rubella, but this is irrelevant.

However, in these cases, the claimants "do not contend that the defendant caused the deformity", Owagage pointed out in his analysis. The claimants pose that the defendant was negligent in making information available to the parents.

To understand the dilemma, it is helpful to compare the situation with that of a five-year-old child being hit in traffic by a drunk driver. Is the driver's liability greater when the child ends up paralyzed relative to when the child dies? Can the child (or the parents) sue the driver because the driver did not kill the child, but paralyzed the child instead? No.

(It is hard to find an exact parallel among cases with five-year-olds, with similar relationships between professionals, child and parents as in wrongful life cases. That said, there is a duty of care toward the child on the side of the driver, and road traffic accidents too are mainly negligence cases. So the comparison seems a valuable exercise.)

Is a child better off when it falls down the stairs and dies than when it falls down the stairs and becomes a paraplegic?

Now consider the case in which both parents are blind and deaf and have just moved to a different neighborhood. Can the professional who sold them the house be held negligent if he or she has failed to inform the parents that a busy road runs past the property if the child subsequently walks into traffic and gets hit by a car? The real estate professional was in possession of vital information that the parents did not have. Had they had that information, the parents might have had a better gate installed so that the accident would not have occurred that affected the life of the child. But would the child (or the parents) sue the real estate professional because the child didn't die?

Such a hypothetical case seems very relevant with respect to the wrongful life scenario, particularly if the real estate professional provided a statement in writing that the house was sound, whereas someone else took photos at the time that clearly show that it wasn't. (We have to ignore that there may be an element of ill will in this example.)

If a house has a brick chimney that is about to fall off, the real estate agent fails to mention this to the blind parents, and their child is injured by the falling bricks from the chimney, that would be like a health professional withholding information from a pregnant woman as a result of which the fetus is affected by rubella. This child, however, would not sue the real estate professional because it is still alive, but the child could bring an action for the damage done by the falling chimney.

Then it begins to look like the distinction between the two different kinds of wrongful life cases is important. It also becomes clear that being alive in itself is clearly not considered “damage” as the child would not take the driver or real estate professional to court because it is still alive.

It then becomes clear that some wrongful life cases do seem to have a real basis, whereas others don't.

In the cases of genetic conditions, when the mother claims that she would have terminated the pregnancy had she had the correct information, the child cannot claim that it would have been better to be dead (with the exception of a life “not worth living”).

If you want to draw a parallel with non-existing versus existing or a different child existing instead, you could consider the fact that one child may get hit by a car while a child standing at a distance of 1 meter does not. Someone who gets hit by a car cannot claim that if he or she had stood in another person's position, the car might not have hit anyone. Someone who does not get hit by the car cannot bring a lawsuit against the driver, claiming that the driver hit the wrong person. Who gets hit by a car or not, that is almost always a similarly philosophical question as occurs when courts are asked to consider wrongful life cases involving genetic conditions. It's almost like curved space-time.

It is impossible to know whether the car might have swerved or spun out of control differently if the person had stood in a different position or if the sun had been shining or the sun had not been shining.

In wrongful life cases in which the mother contracted rubella, it makes more sense for the child to sue the mother than the physician, but not for the fact that the child or resulting person exists but for the fact that a physical change was caused against the child's explicit will. This, however, is currently not a reasonable course of action. A mother has no control over whether someone who for example happens to be on the same train happens to infect her with rubella or not. A possible exception could be when the mother knew she had rubella, and then deliberately became pregnant.

A different exception would be when a lab, hospital or medical

profession, for example, has advised a mother that she does not have rubella (or is immune to rubella), after which she then goes ahead and becomes pregnant almost instantly, after which the fetus is affected by rubella after all. There can also be cases in which the mother, for example, uses medication and is told that it is safe, should she become pregnant and then the medication turns out to have some teratogenic action. Such a pregnancy could have been prevented, so the negligence did actually lead to the “damage” in such cases.

Talk about obliging mothers not to smoke, not to use any drugs and not to consume any alcohol during a pregnancy and the criminalization of breaches of such a duty does crop up from time to time. (Gradin v Gradin was a case in Michigan, in which a child sued his mother for having taken drugs during the pregnancy, but the mother was unaware that she was pregnant.) Lawsuits of a child against the mother for negligence during the pregnancy are not allowed in many jurisdictions. In Britain, the Congenital Disabilities Civil Liabilities Act 1976 covers it (makes it impossible), for example.

It is generally thought that the relationship between a mother and her unborn child is so special that to make the mother liable for anything that happens to the fetus would infringe on her rights as an autonomous person. Negligence claims for careless driving with the child in utero have on occasion been upheld, but seem to be covered by motor insurance, in practice. Other than that, these cases are just as controversial as wrongful life claims, as to hold a mother liable would essentially stop women from leading their lives while pregnant.

Here too, the cases center on the need to finance care for the resulting children; see for example the British case *CP (A Child) v First-Tier Tribunal (Criminal Injuries Compensation) & Ors*.

So far, in wrongful life cases in which courts awarded damages, the essence of the claim is usually wrongful birth, with the difference that the award is made to the child instead of to the parent(s). This can help safeguard the child’s care in case the parents die or separate. Questions such as about the parent’s right to an informed choice are wrongful birth, not wrongful life considerations.

These cases are often clearly not only linked with the topic of medical malpractice but also with any nation’s duty to assist its citizens. That is often the real motivation for wrongful life (and wrongful birth) lawsuits. Perhaps this problem should be addressed through class actions, where possible.

In France, the *Perruche* case led to new legislation (in 2005) that ensures

financial support for families in the event of the disabilities of children, albeit only toward covering basic needs. Britain, for example, was found to be “blatantly discriminatory” against certain groups of disabled or chronically ill citizens by the High Court in December 2017, affecting 1.6 million people but likely benefiting up to 220,000 people in back payments, unfortunately possibly taking several years. The British government had already been informed similarly by a tribunal, but then rewrote the law to avoid having to follow up on that outcome.

This entire discussion also seems to force us to have a discussion about the rights of embryos and fetuses again (see Chapter 7). Does a fetus have a right to life or not? Does a fetus have the same rights as a five-year-old child? Does a fetus have a right not to be harmed? Does a fetus or embryo have the right not to be discriminated against? Can a fetus have a right to be killed?

What does the law say when someone kills a pregnant woman in such a way that the child dies too? Is this one homicide or are these two homicides?

Different jurisdictions deal differently with this question, but a common view appears to be that killing a fetus that is viable outside the womb constitutes fetal homicide. The right to abortion is also often tied to this viability question (and this is about to become muddled, as Glenn Cohen of Harvard has pointed out, with the advent of artificial wombs).

Generally speaking, we do not seem to assign the full set of human rights to fetuses as a prevailing view appears to be that if the mother’s life is endangered by the pregnancy, ending the pregnancy is permissible. This is certainly not true in all countries, however. In some countries, such as El Salvador, there are currently problems with the criminalization of women who have had a miscarriage or stillbirth because these women are suspected or accused of having caused the miscarriage or death of the fetus.

What, however, about children who end up with a life not worth living if this could have been prevented? If I follow my own definitions, such children would have a cause of action in wrongful life cases, as in such cases, life itself could be considered “damage”. The “immoral” quality of this conclusion implies that we have a moral duty to apply CRISPR toward the remediation of the related conditions.

There should be a standardized provision of support, including counseling after the birth of the child if the child turns out to be a non-mainstream child that requires extra support. Ideally, all parents should receive whatever level of support they need. As I’ve mentioned, I think we’ll see a shift in professions in the future that will enable this, for

example, considering the immense support males have had in the past, from their spouses, which allowed them to be fully dedicated to their work to a degree that most women still don't have.

Many countries already have support like this in place. If you picture parents having to lift a child all the time and someone needing to be around all the time, you can quickly see that such parents deserve practical and psychological support, not in the least for the child's sake. Such parents require lifting equipment and common sense says that they also need to be able to take the occasional evening off and the occasional vacation in spite of needing to provide the physical care for their child, for instance. In many cases, they would likely require a dedicated carer who is familiar with the child and the circumstances, instead of having to face a new carer every time.

The concept of wrongful life is connected to the idea that this non-discriminatory guideline for the new eugenics obliges us to couple it with euthanasia legislation. Indeed, I believe that we would need to complement such a restrictive (non-discriminatory) eugenics practice as I propose in this book with matching legislation for euthanasia and physician-assisted suicide (see also Appendix E). If we allow someone to come into the world – particularly if that person would have passed away naturally if we hadn't interfered – and that person considers his or her life not worth living as an older child or adult, we must also allow that person to act on that belief. That is only fair. Moreover, I believe that this, too, is part of giving someone the right to live his or her life in dignity.

Keep in mind that even if a person feels that his or her life isn't worth living in the present moment, the hope that this will change in the future, for whatever reason, is usually enough to keep someone from exercising any right to euthanasia or assisted suicide. This is also linked to the moral obligation we have to use techniques like CRISPR first to address conditions that currently still lead to lives "not worth living".

The literature listed at the back of this book contains several examples of actual wrongful life lawsuits, such as the case of *Curlender v. Bio-Science Laboratories* in the U.S. This concerned a normally conceived child with Tay-Sachs disease, with a life not worth living according to the definition that I propose. The child's parents had undergone blood testing with the specific purpose of assessing whether their offspring was likely to have this condition. The lab was somehow negligent in how the blood tests were conducted.

Turpin v. Sortini et al. was a very different case that came before the U.S. courts. The Turpins' first daughter had been examined and tested

and incorrectly declared of normal hearing, whereas she was actually completely deaf as the result of a genetic condition. The Turpins then had a second daughter who had the same condition. They stated that had they known about their first child's hereditary deafness, they wouldn't have had the second child.

According to the reasoning I present in this essay, it would have been okay for these parents to decide not to have any further children at all because it cannot be called discriminatory. If the parents tested for the condition in an embryo or fetus and found it present, however, then this should no reason to deselect the child as the child would have a life worth living. To decide differently would be discrimination.

To seek damages for emotional distress suffered by these parents (which the Turpins did, among other things), because their child was deaf is also a form of discrimination. A high-IQ child would demand a similar level of care. And who is to say that a hearing child with a normal IQ would require less care? Would the parents have sought damages for emotional distress caused by the fact that they unexpectedly had a child with a high IQ?

In Germany, wrongful life claims are unconstitutional, as such claims would imply that the life of a disabled person is less valuable than that of a non-disabled one. The judiciaries in England and Wales, Ontario, and Australia mostly feel the same way.

The Netherlands, on the other hand, has had the case of Kelly Molenaar. This concerned a nine-year-old girl who was born with a serious chromosomal condition, as a result of which she appears to be in constant pain. I think it is fair to see particularly pain as a real impairment as opposed to impairments resulting from hindrances created by society. The child has other problems as well and, for example, had several heart surgeries. At age two-and-a-half, she had already been admitted to hospital nine times for incessant crying alone, and this was believed to be caused by pain. Kelly's chromosomal condition runs in the family, as a cousin of the father had the same condition and the mother had already had two miscarriages. The medical profession did not follow up on that information, even though the mother had made it available. No family history was taken and there was no consultation with genetics experts. The child's condition was therefore detected too late.

The Court of Appeal in The Hague refused to consider a handicap "damage". However, not only were the parents awarded costs of care and upbringing until the child's 21st birthday, and costs of psychiatric care for the mother after the birth, the court also made the child a party to

the case. The case was referred to the Supreme Court (on points of law), which upheld the Court's of Appeal's finding. Kelly was awarded compensation for emotional damage, which would not have occurred if the medical professionals had done their job properly. The court stressed that it had based its damages on the fact that the medical profession had made serious mistakes, not on Kelly's existence as such. After this case, there was a call to ban wrongful life cases in the Netherlands, but no change in the law appears to have come from that. It remains a very difficult topic. In the case of Kelly, one can argue that Kelly's pain could have been prevented and that this is what the Dutch courts mainly based their judgments on. This child is suffering, objectively seen.

France has had the already mentioned successful wrongful life claim of Nicholas Perruche. This concerned a boy born to a mother who contracted rubella during her pregnancy after one of her other children became ill with rubella. Despite two lab tests and symptoms, the mother was informed that she didn't have rubella and she continued the pregnancy. The French boy's parents brought proceedings on behalf of the boy when he was 6.5 years old. Apparently, he has a heart condition and is deaf as well as blind; he may have other neurological conditions. The family first went to court in 1988 and was awarded approximately USD 13,000 (for wrongful birth). The parents, however, also felt that Nicholas himself had been harmed by the laboratory and the physician. Nicholas was awarded damages four times, which was reversed on appeal every time until the case made it to the Cour de Cassation. In this case, too, the medical profession made serious mistakes, but the crux of this case appears to have been financial support for the child's care and in this case, the award to Nicholas was for the handicaps, in contrast with the Kelly Molenaar case.

France did later (2002) ban wrongful life cases, but it also created a law (2005) that arranges basic care for children like Nicholas Perruche. That is a very important change. Many of these situations hinge on whether or not the parents are able to look after the child well, in terms of financial means. In the U.S., the parents of Juliana Wetmore not only are looking after their daughter wonderfully well, they also adopted a child with the same condition (Treacher Collins Syndrome), from another country. Allegedly, it is their Navy-based insurance that makes this possible.

I feel that I do not have enough information to be able to assess whether the cases of Kelly and Nicholas concerned lives not worth living, according to my definition. It certainly appears to be the case for Kelly, but the situation of Nicholas is much less clear and I am not convinced that his life is not worth living.

The cases of Kelly Molenaar and Nicholas Perruche make clear that not only can there be major differences between individual cases, they often have an element of punishment. This is for clear professional negligence (medical malpractice), similar to mistakes like amputating the wrong leg or failing to diagnose cancer that could have been cured if it had been treated instead of misdiagnosed. I think that we have to deal with this separately, not tie it to the lives of the children, however, while nations should step up in the provision of care, the way France has done.

Parents should not be forced to go to court to secure care for their child if that child requires more care (such as multiple surgeries, in the case of Juliana Wetmore) than the average child. Parents should not have to deal with that immense stress. Children (even if only theoretically, considering that the knowledge may remain out of reach of the mental capacity of these children) should never be burdened with the knowledge that their parents felt that they should not have been born.