

# A Right to Be Born ‘As Is’?

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## ABSTRACT

The prospect of the use of gene editing for future populations may not be imminent, but its permissible use is gathering speed. Advanced understanding of the human genome, gene editing tools, and the procedures for potentially life-changing applications are challenging prevailing norms. As a result, our obligations towards future generations may be augmented by advances in biomedicine. In face of these proposed benefits, opposition has been raised against the use of editing on grounds that its use will question the very existence of human being and will violate or damage specific understandings of dignity. As such, if dignity can be defined and will be violated through the permissible use of editing it is feasible to establish a right to be born ‘as is’, that is a clear trajectory from conception to birth without the intrusion of genetic editing or human implemented genetic modification. I argue that there is an intuitive basis for this type of right but that it struggles on the weight of other rights and the interests of future societies. Aspects of the right could be salvaged but the prospect that future generations be edited for their protection must remain open as an option for present generations.

## 1. Introduction

Gene editing and Germline Intervention (GI) for use on future generations may not be imminent, but its permissible use is gathering speed. Advanced understanding of the human genome, gene editing tools, and the procedures for potentially life-changing applications challenge prevailing norms. As a result, our obligations towards future generations may be augmented by advances in biomedicine.

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In face of proposed benefits, opposition has been raised against the use of GI on grounds that its use will question the very existence of the human being and will violate or damage specific understandings of dignity. As such, if dignity can be defined and will be violated through the permissible use of GI it is feasible to establish a right to be born ‘as is’, that is a clear trajectory from conception to birth without the intrusion of genetic editing or human implemented genetic modification.

This paper will outline what a right to be born ‘as is’ (RBAI) would look like, its intuitive defence and potential benefits, and why a heavy-handed approach disregards the interests of future generations. Firstly, I shall outline the ‘as is’ scenario and its philosophical foundations. Secondly, I shall outline the grounding and the concept of the right. Thirdly, I will review competing interests to ground the right.

## 2. The ‘as is’ scenario

The basis of the ‘as is’ scenario builds from an assertion that editing on the serves ‘no moral purpose’ (Centre for Genetics and Society, 2019). For GI to have no moral purpose there must be a moral value on the genes and genome that places this value as a pinnacle of humankind. As such, three assumptions can be drawn to guide this discussion.

The first is that the germline should be ‘unchangeable’ to retain its moral value. In essence, the genome and/or genes are considered sacred. However, there is a necessary difference if the genome is considered sacred or the genes. For instance, we could have 23,000-34,000 genes but not all function and they also change expression. If the genome is sacred, changing one gene, no matter which, will, under this theory, fundamentally change one’s genetic identity. This supposes a fixation on the house (the genome) and not the expressive qualities of the residents of that house (the genes). Editing is concerned with individual genes, not the entire genome, and changing the composition to avoid negative effects. As such, the focus on genetic links to identity should be on the effect of those individual genes rather than holding the entire composition of the genome, as it was in gestation, sacred.

The genetic continuant as ‘sacred’ is used to argue that a genetic edit changes the identity of the individual. Although this discussion does not have space to go into the theories of human identity, my contention is the continuants of our identity rest in our psychology and that these can change based on

our choices, historical evolutionary change, environment and can even incur epigenetic change which change the expression of genes (Carey, 2012; Dupras, 2014; Sigman, 2017; Turner, 2020). Through our psychological continuity we develop our identity and create an imprint of ourselves through genetic expressions. Thus, we are influenced by our genes, but not only our genes. The grounds to treat the genome as sacred, on the precept that it protects the dignity of the species, is too limiting for the species. The violation of the sacredness changes the integrity of the genome and thus the personality, and rights and dignity, of the subjected individual.

Secondly, the essence of the human 'lies within the genome', meaning that RBAI must promote the principle that 'we are our genes' which suggests that changes to the genome is to change that essence. This assumes that editing changes the germline between generations in a way that is not natural (or cannot be done any other way). 'Natural', in this context, shall mean that the trajectory from  $t_1$  (conception) to  $t_2$  (birth) has no *intentional* human induced interferences. As such, there are necessary allowances for evolutionary change and change from environmental or dietary factors. Whilst it is fair to assert that we are a result of our genes (as without them we could not be born) it is a far cry to say that we, as behavioural functionaries with personalities, *are* our genes as an absolute statement. To justify a rights violation over editing on the basis that the human is essentialist and drawn from the genes and will seismically change from as little as one gene changing or that a whole person is different (without knowing what the person would otherwise be like) is to give genes the ultimate fatalistic role to determine the nature of all humans so that the rights of the edited individual are violated because their 'life-script' is already written from them. As such, the edited are no longer an individual and their standing for rights is jeopardised. At worst the edited become 'unnatural' and may go as far as being considered unhuman, which strikes at the point of inalienable human rights.

Through these premises and the issues that opponents of GI raise (which I shall outline further), such as the limits to individual identity, genetic integrity as a continuant for that identity, and that the individual is genetically determined to the point that an edit will 'control' the resultant life (Fukuyama, 2002; Habermas, 2003; Sandel, 2007). These concerns can inform RBAI thus:

1. Each prospective individual has the right to have been born with genetic integrity from their forbearers.

- a. This right re-affirms the international community's prohibition on human genetic experimentation if this experimentation is to bring them to human life.
- b. The self-determination of all peoples under human rights as a definitive inalienable interest to all that enter human societies as a human being requires that no impasse will be made to change the natural perspectives of that individual during the time of gestation that changes the genetic integrity of the imparted genes from their forebearers; or to be intrinsically *pre-determined*.
- c. Genetic integrity means that the born individual will have an untampered genome and that this conveys their dignity.

### 3. The right

The position of GI in European law is mixed. The use of editing for research purposes is generally permitted but heritable changes are not allowed to be used in a human embryo that will be brought to term (Regulation (EU) No.536/2014; *European Convention on Human Rights and Biomedicine* (Oviedo) (1997); the UK's Human Fertilisation and Embryology Act (2008); and these concerns are raised internationally in the *UNESCO Declaration on Bioethics and Human Rights* (2005), art.2). Ostensibly, the international position is to protect the present and future from unsanctioned actions on the grounds of safety and transference but are keeping open the door of genomic research which can only be for the prospect that it will be used in the future. The grounding criteria across these documents, which is slightly more elucidated than many other human rights documents, is 'dignity', a term that I shall return to later as it is a term consistently used to justify the documents themselves, but are similarly consistent in not offering a clear definition of 'dignity' (and, due to the bioethics declarations, regulations and conventions, RBAI would be grounded in a similar view of dignity). Before looking at the grounding of the right, I will discuss some rights that may inform RBAI.

RBAI could be constructed through appeals to other rights. The most appropriate candidates with regard common objections to GI would be the Right to Life, the Prohibition of Slavery, and Freedom of Conscience. In the context of GI, the Right to Life would require a new and limited interpretation to include embryonic rights, on the proviso that the individual is intended to be

born, unless a condition causes their expulsion. The Right to Life does not venture into the question of when life begins (*V.O. v France*) nor too far into what the life should contain (*Pretty v UK*). RBAI, through the Right to Life, would be a limited aspirational right to protect the genome as a primary value for the Right to Life. A future person has an interest to be born, they also have an interest to have a condition that provides them with the means to access opportunities which exceeds the meaning of the right, exemplified by the reluctance for human rights documents to enter questions on when life begins to focus only on the arbitrary deprivation of a life.

If the Right to Life is too limited, then perhaps we must look at the values within the life that is born, specifically if it is known that a human rights abuse will be set in motion during gestation. Annas et al. (2002) proposed an *International Convention to Preserve the Human Species* which infers that GI could reinstitute slavery. However, if it were possible to genetically edit a person so that they have no ability to consider their own situation and be brought into slavery this would already be a violation of the Prohibition of Slavery when they are born. The danger of placing GI in the historical context of slavery (and its ongoing scourge) is that *any* use of GI can be accused and severely limit, or diminish, the potential life-changing values of GI rather than seeking reasonable limitations on its use.

Annas et al.'s concern is with the 'species-altering' technology that saps away the uniqueness of the individual making them a 'slave' to the technology that provided them their gifts (Sandel, 2007, holds a similar view that the giftedness of humanity will be eradicated). Perhaps the idea is to reimagine the slave. Rather than being an outward slave, GI creates an inward slave. By being edited a specific element of our humanity is removed and the individual fails to be self-critical as his genes are expected to answer all the question of their life (Habermas, 2003). For the living individual, who is born after editing, they would more likely consider any editing, that can be shown to unduly affect the ability of that person to use their talents (natural or edited) to determine their own future. Indeed the 'slave' loses self-determination, but in this case, as editing, as an action, cannot be shown to be part of the institution of slavery, the living individual's concern will be whether they truly have Freedom of Conscience.

Freedom of Conscience can be inferred to claim that the edited will lose their cognitive freedom to know thyself. Sandel (2007) argues that the edited will have been designed to a specific purpose. Habermas' objection to GI ar-

gues that the edited will lose the ability to be ‘self-critical’ (2003). Together, these views suggest that an integral part of being a human is lost purely by an edit (rather than stipulating what type of edit). As such, the born have already lost the ‘freedom’ of the Freedom of Conscience and are driven, by their new genes, to reach certain ends. This implies that the edited will have an internal struggle between what they are and what they ought to have been and this overlaps with the restatement of the Prohibition of Slavery. However, invoking slavery has far too much historical and social significance to justify being born ‘as is’, but Freedom of Conscience may provide the most relevant grounding within the context of the resultant individual being a ‘doing’ rather than a ‘being’ with the ability to consider their own self-determination.

RBAI can conceivably claim an affinity with the Freedom of Conscience, but it is relatively abstract necessarily to state that the edited will lose this freedom and thus it is permissible to outlaw it. Rather, RBAI requires further grounding is required to determine if the issue is the development of a conscience, which could be considered dignity as innateness, or the use of conscience, which would be considered dignity as autonomy.

#### 4. Dignity

RBAI argues that the integrity of humankind is under threat from GI and that our dignity as a species is linked to the genetic integrity passed down by our forebearers. Conceptually human rights would anchor similar claims under the terms of dignity. RBAI, which could be understood with Freedom of Conscience and a related interpretation of self-determination, would require an element within the right to justify the value of the right as it exceeds the sole value of Freedom of Conscience. As explained earlier, dignity has been used to expand upon and develop new rights or understandings of rights. The Conscience that is threatened by the edit is philosophical and cannot be shown in real world cases in the sense that the edit, in real time, has stopped the individual acting on something. Rather the arguments by Habermas and Sandel are that they drive a person to the interests of the creator and not the individual themselves. Thus, two elements are at play, firstly that an innate element of the human is missing or violated – we can call this innate dignity – and secondly, that the ability of the human to act in a ‘true’ way suffers – we can call this dignity of autonomy. Before these discussions, the premise of where dignity sits in human rights and philosophy.

The use of the term 'dignity' was notably criticised by Macklin as overused to the point it has become a 'useless concept' (2003). A term being overused does not in itself make it useless, but the incoherency and lack of substantiation in the application of the term affects the comprehensive understanding of term and its subsequent use as a justification of a human right.

Dignity is commonly argued to ground human rights and is used to frame several human rights documents but often appears more aspirational than definitive. Dignity is linked to the freedom the rights are meant to provide (*Universal Declaration of Human Rights* (UDHR), 1948, art. 1) offering a circularity to the grounds and rights where one must respect the rights to respect dignity and respect dignity to respect the rights. The term is not used in the *European Convention of Human Rights* (ECHR) (1950) but has been used in rulings by the European Court of Human Rights, although on an individualistic basis rather than over the 'human family' and only to 'enhance' the interpretation of convention rights (Marguenaud, 2018). By contrast, the more recent *Charter of Fundamental rights of the European Union* (2000) states that human dignity is 'inviolable' and must be 'respected and protected'. In more niche documents the terms of dignity are slightly more elucidated, for example the *UNESCO Declaration on Bioethics and Human Rights* (2005) links dignity with autonomy where the 'unique capacity of human beings to reflect upon their own existence'.

'Dignity' is raised when there is an action that impacts negatively on human societies and has been used as a justification of the enhancement or expansion of rights, such as to justify the distribution of healthcare as a human right or expand the notion of degrading punishment. However, how dignity is affected is multifaceted where it can be harmed by any violation to a right, thus the value of my loss of expression is not only that it reduces my participation but, by doing so, it affects my dignity. In the case of *Tyrer v UK*, the first time the European Court used the term 'dignity', the expansion of degrading punishment to include corporal punishment was an affront to dignity, but arguably the expansion could have been justified purely on the grounds of art.3 and thus fails to answer why degrading punishment is not enough on its own to justify expansion. The same could be said about the expansion of the criminal act of rape to acts within a marriage (*C.R. v UK*, 1995; *S.W. v UK*, 1995) which are heinous acts that reflect the power dynamic within the contract than the actual dignity of the person.

But dignity is also not separate from the right and is not used in conjunction with a violation as is the case with anti-discrimination rights. Thus, the right appears to need dignity to be justified but the right is needed to understand dignity which present a circular dynamic that one must care about dignity to care about their right and the right must be cared for to justify human dignity. As such, dignity could become ‘not a state of being, but a feeling’ (Feuillet-Liger, 2018, 302). It is this idea of dignity as the grounds of the right and the also as the value of the right that causes its vagueness, and this is where the conundrums lay.

The vagueness can allow or disallow an action on specious reasoning, and this is telling on questions of autonomy and capabilities. This dual meaning can be used as a sword to attack interpretations that states and societies do not like and not on the weight and value of the question itself. The conflict rises as the use of dignity can be seen as an empowerment claim, which holds a positive view of human rights and what an individual should expect from a free life. And a constraint claim, which appeals to wider social values to determine the value of dignity and can forbid actions that an autonomous person would take for perceived breaches of dignity (Beyleveld and Brownsword, 2001).

In sum, ‘dignity’ appears like a ‘catch-all’ for rights as it implies that dignity is necessary to understand the right and to give reason to pursue the right. In national contexts, dignity is often invoked to provide moral substance to a law and a violation. On moral questions regarding technologies that have both potential positive effects and potential negative effects the term ‘dignity’ could be problematic and condemn a swathe of people under the guise of protecting dignity or be used as a sword to settle moral questions the value of which are hard to ascertain.

## 5. Dignity as an inherent value

There are many ways to look at dignity, more importantly for a comprehensive view for a technology that has universal application as it acts on the genes, not the culture. But it must not harm competing interests as understood as grounded in ‘dignity’ to be a right.

Dignity as part of a human family is referenced in international human rights documents, such as the Universal Declaration of Human Rights (1948), and implies that dignity is inherent to humans (although this does not imply, by the terms of the Human Rights documents, that it applies prior to life). In this



sense, no rights-holding person can escape dignity. If GI can affect the dignity of the individual by violating genetic integrity between  $t_1$  and  $t_2$  then the dignity of these individuals begins prior to life, as if the genes themselves carry the dignity. This places GI in the crosshairs depending on how 'dignity' is viewed as RBAI, following international norms, cannot express what dignity is or how it ought to be manifested on individuals. We can analyse this view through the lens of the 'sacred genome'. Sandel's *The Case Against Perfection* (2007) argued that a society could become transfixed on perfection when they believe that they can change the genes of their offspring and develop them for specific ends. The giftedness of these children will be reduced, and an economic structure will take over selling traits for wanting parents. Humankind will lose its moral centre as it seeks the enhanced over the natural and the results over the effort.

For Sandel's concern that the parents of the future will construct their kids through the selection of genes and thus ignore their 'natural' gift in place of assured ends requires a strict adherence to the natural lottery. As such, innate dignity must be protected through constraint and through this protect our genetic integrity. With dignity as a constituent part of a right, and GI negatively impacting dignity, GI becomes antithetical to rights. This not only implores that our genes carry our dignity as to intervene will reduce their dignity and their 'gift', but also advances a moral reason to 'freeze' the genome at a time *before* their could be editing to protect the sanctity of 'natural' genomes.

However, retaining the natural lottery may not bring the outcomes Sandel proposes. Firstly, it must ensure that the presupposition that our genetic endowments contain the continuants of our identity and that our identity is changeable through the change of genes. Whilst the natural lottery would stop intended genetic change, it would not stop unintended genetic change. It is justifiable to accept that changes in epigenetics and gene expression that can occur through environments and evolution (in the long term) must be acceptable. But it calls into question why would GI be treated different if the expression of the gene can change anyway? Certainly, any action by parents that could also cause a negative change in genetic expression should also be shunned.

Secondly, the societal push for some GI will likely occur if specific genetic cases become more publicised, and more research on the prospects of GI are known and it would be understandable that in the face of significant hardships the moral evaluation of GI in a society will change. Where the society may have used the constraint form they may look towards the empowerment form to re-

duce the challenges caused by this, and other, genetic conditions. Granted, for Sandel this would be the beginning of the free-market eugenics where people 'buy' these traits, but it is unclear if the limits of society would opt for this and limitations are put in place, or if the free-market eugenics were allowed that anyone would want a full-scale genetic overhaul of their potential child, rather than a measured approach that isolates known genes and genetic cluster that may affect the open future of the child. There is a conflict that Sandel argues that parents of the edited will lose love for their child but ignore the multitude of reasons they may opt for the edit, no less that most parents want a significant genetic link to their children.

Sandel's objection for free-market eugenics is fair, but this is a problem of our current funding cycle which provides more emphasis for private scientific research which propels a for-profit model, and in these cases the genetic intervention to stop Tay Sachs would be less valuable than an intervention that purports to increase IQ by 15 points (I will discuss how this could be quelled through the capabilities approach in the next section). However, a legitimate aim will be formed for a multitude of potential diseases and effects that harm the individual's lifespan, quality of life, and access to opportunities. But Sandel's view is concerning for greater reasons, specifically that it restricts the present and the future away from the benefits of scientific knowledge that can deviate from the natural lottery model. It could be argued that the conflict has already been lost with the prospect of genetic testing and abortion or procreative beneficence where several eggs are fertilised and genetically screened giving a choice to the prospective parents on which to bring to term. Rather, relying on the natural lottery not only links dignity to the method of birth holding a natural one to be the most moral but reduces other methods to reduce the likelihood of transference of genetic diseases, such as manipulating an egg with cells from two donor eggs to avoid mutations in mitochondrial DNA, the genome will still be natural, but the trajectory will not.

And finally, just because traits are on offer it does not mean that the life is pre-determined. For example, there is a difference between giving someone the genes to be more athletic with the aim they will be a basketball player and that individual becoming a basketball player. Whilst genes may assist in some aspects of sporting achievement, it take more than this to be an athlete, the individual requires drive and support. And the expression of other genes that relate to the choices that the individual makes, which may also, autonomously, lead them down a new path where basketball is less interesting than marine bi-

ology. However, for Sandel this criticism should not hold as the intended act by the parents was to create a future for the children through intervention, and not through parental care and assistance to cultivate talents *of the child's choosing*. It is however instrumental on how futile the editing could be against the greater power of the Freedom of Conscience of the resultant child to draw from the thousands of other genes and other external influences and choose another path than the one expected.

The extended problem is whether the genome can be frozen in time or that level of genetic integrity to be retained for the future is wanted. By extension, this implies a power of the genes over us that we cannot resist. This is likely a miscalculation on the part of Sandel. As Juengst appropriately observes 'the human gene pool, unlike the sea, has no top, bottom, or shores: it cannot be 'preserved'' (Rasko, 2006). That is not to say it can be plundered like the seas, rather it is living and must be used with care. If we freeze the genome, we are disregarding how the process of science operates, the interests of future generations to be included, and ignore that natural genes freely found must not fatalistically be embedded into specific individuals purely by luck but could be considered common heritage to be utilised for the benefit of many.

## 6. Summary

RBAI has a problem by stating that the individual must retain genetic integrity as this could be informed by retaining the natural lottery as a way to protect dignity. The implication that human dignity begins prior to life is problematic for several reasons, one of which is how it would challenge the actions of the would-be parents during pregnancy but also because it becomes abstract from the meaning of rights. It cannot be considered that our dignity is transferred through the genes, the genes are what help make the individual (we do the rest) and this view disempowers the individual and falls into the mode of genetic determinism. Richard Lewontin argued that modern genetics overestimates how far an individual is genetically determined. He feared about giving too much power to genes, arguing that it will allow us to determine who is weak, who is poor, and why some civilisations fail and will 'justify inequalities' without proper examination of the root causes (1991). Rehmann-Sutter argued that 'the idea of modulating the human genome to fit human plans and desires is stuff for fertile imagination and intellectual creativity' but 'the power of our genes over human identity is sometimes predicted by lay participants to be enormous'

(2006). It could be argued that by holding to a sacred genome and the natural lottery, when potential alternatives are possible, falls into the trap of justifying inequalities to object to the humans that may use GI.

### 7. Dignity as autonomy

Thus far, dignity has been considered overused and incoherent, and the prospect that the same idea can be used to curtail a freedom on the same grounds it could grant one is problematic and only adds to the vagueness problem. It is plausible that dignity is used in rights without meaning to merely denote a value to the right, like a catch-all. However, as explained earlier, the value of the right ought to be the right in that we ought to recognise that putting someone in prison on no charges is the wrong thing to do morally and in light of how I as an individual would want to be treated. As such, as inferred by Feuillet-Liger (2018) dignity can be invoked to answer a question of conduct without full validation of the term. Dignity as autonomy suggests that dignity need not be innate in the person, but when the individual is here they should have the freedom to act as themselves. As with dignity as innate the opponents to GI argue that the edited will lose dignity as the edited cannot have autonomy as their lives have already been pre-determined by the edit.

Kantian autonomy is the most common interpretation of autonomy. Kantian autonomy implies that there is a duty to act morally to the self and to others, specifically to maintain opportunities for all so that decisions over their lives have meaning. To 'act morally' is a fairly open term, and can change in value based on the society the individual is in. The human rights regime should be a guide for these moral actions, but, as Feuillet-Liger argues that invoking dignity with freedom is problematic as when dignity is used to increase or restrict a freedom it is most often used to support opposing views. Indeed, the Kantian view can develop into a dual meaning where there is empowerment through some actions and constraint on others, but that the line is unclear and could lead to dignity being used as a sword to pursue state or societal objectives against true values of autonomy.

In the context of biomedicine, 'dignity' is increasingly invoked as a value imposing limits on the individual's right to self-determination' where 'dignity becomes a means of limiting the freedom of individuals in situations where an individual claims the freedom to use his or her body' (Feuillet-Liger, 2018). Thus, end-of-life issues appeal to dignity on opposing sides and justified on

how it serves their argument, not to further a comprehensive idea of dignity itself. The term can be manipulated where 'the extent of the liberties granted to individuals is not related to dignity' (Feuillet-Liger, 2018). This suggests a problem with a universal view of dignity, which a right would require, against the constraint or empowerment view on a case-by-case basis.

An interesting case to emphasize the problem of vagueness, constraint and empowerment is where an individual partakes in an action where the only danger is to themselves but where there is a societal question over whether it is right. A case was presented before the French Conseil d'Etat of a little person who hired himself out to be used as a projectile for a game reminiscent of darts. The French court ruled that 'Dwarf Tossing' breaches his dignity and denied him the right to continue as a practitioner. Both the constraint and empowerment view were at play. The Court adopted the constraint view to state that it is not dignified for an individual to use their disability in a way that treats them like an object. The little person used the empowerment view where he has taken advantage of an opportunity that was presented to him (and it could be argued, under the social model, that he no longer has a disability whilst engaging with Dwarf Tossing because he is able to do something others cannot). If dignity as autonomy includes human flourishing then the little person could claim that he has a greater opportunity to frame his own future through Dwarf tossing than in other economic pursuits.

The French court was paternalistic in their view of dignity and could be argued that they harmed the rights of the little person in terms of remuneration and opportunities (UDHR art.23(3)), reduced his living standards (although, they likely remained 'adequate') (UDHR art.12) and reduced his freedom of expression (ECHR art.10). As the case was not about the clients who use the service, there are no questions on whether they engaged into the game purely because they want to sap away the dignity of a little person, it purely relies on whether the action itself is degrading.

The little person is pushed from two sides. First, his participation led to the accusation that he is degrading himself, which also removes the freedom to act to other little people and presupposes that their dignity, as a group, has been harmed (although, the European standard for rights is on the individual). Secondly, that the constraint view could favour a form of dignity as a means to reduce another right, specifically his expression as an already vulnerable person, no less that it presupposes that he does not know his own values. The little person has committed no crimes and has not breached the rights of others, but his

autonomy is questioned as if to say that they accept that he has an economic incentive, but this is not what he *really* wants to do. The court appears to use dignity in the catch-all mode for the right to try and justify the abridgement of his freedom (although, France is not strictly libertarian, any European state must have legitimacy in their ruling to outlaw a practice).

The case is important as it is instrumental of how flexible dignity, and to a lesser extent autonomy, can be over controversial questions, which are common in biomedicine, for example permission to harvest stem cells and assisted suicide, both of which have had their trajectory to limited acceptance thwarted by versions of dignity, such as when assisted suicide was denied to a terminal patient who argued they are not living in dignity but could die in dignity (*Pretty v UK*).

Ostensibly, the little person has almost all the capabilities that an individual requires to participate, only their height and some minor medical issues may stand in the way, but he has tried to use these as a capability itself. It is fair to look at the characteristics of the autonomous person and where dignity could be retained by assessing the capabilities required. For example, Raz's (1986) view on autonomy is based on the level of capabilities the individual has protected which in turn serve their autonomy through access to the average opportunities of the average person. Raz explained further that human dignity 'entails treating humans as persons capable of planning and plotting their future. This respecting people's dignity includes respecting their autonomy' (In Beyleveld and Brownsword, 2001).

In contrast to the retention of the natural lottery, Raz's empowerment could see an investigation into specific genetic conditions and the likelihood of their undue interference on individual capabilities. As such, we have an approach of fairness, as a 'capabilities index' could be devised to set the threshold of necessary capabilities (or 'Normal Functioning Parameters' (NFP)) and then link them to specific genetic conditions to justify the use of GI for the legitimate aim of ensuring that all people have the basic requirements for participation (where these are genetically understood). The individual will still have to apply themselves in the world, but they will have a fair set of tools to achieve.

The multi-factor threshold for NFP and capabilities would include the lifespan threshold (for example, over 20 years), a pain threshold, and an engagement threshold (the abilities to take advantage of the average opportunities of the average person for reasons other than pain or lifespan) would provide the legitimate aim to protect GI on the grounds of dignity as autonomy.

The legitimate aim will be understood as a right where 'adequate living standards' (UDHR, art.25) recognises the necessity for capabilities to maintain living standards as a way to act against the extremes that a free market may place on these traits.

For example, a genetic condition like Tay Sachs would be eligible for GI for it would render the individual too low on the threshold of lifespan too high on the threshold of pain which will significantly affect their autonomy and access to opportunities. A condition like Lesch-Nyan syndrome (LNS) would present more of a challenge, but as the threshold is not predicated on direct comparison, whilst the lifespan of LNS is longer than Tay Sachs, it is still shorter (and with high intensities of pain) than a qualified average and would be eligible for GI. And although not a genetic condition, Down Syndrome is commonly raised as a condition of low hope. However, against the threshold they would, on average, satisfy the threshold for lifespan and for pain and would require compensation for access (which may be solved by editing into the genome to compensate, or through other reasonable accommodations). Dignity would be preserved on the basis of rights as the legitimate aim is there and measured for the access for the benefit of these individuals and autonomy would be upheld in its truest sense.

By contrast to the prospect of developing a legitimate aim for GI on the basis of protecting the grounds to individual autonomy, Mintz et al. (2018) similarly use autonomy as the basis to object to GI. Mintz et al. adopt an interpretation of Kantian autonomy which incorporates the 'evolving intrinsic rights' of the foetus as a potential source of autonomy. These 'evolving' rights, of which there are little foundation, are somewhat irrelevant if the problem is that GI makes the edited individual only an end. Mintz et al. argue that GI would ignore these 'rights' and 'permanently change the genetic fabric of the embryo and subsequent generations disregard[ing] future autonomy' (2018). As such, Mintz et al. hold a similarity with Sandel (2007) that the value of edited offspring is somehow lesser than those from more natural means. And indeed, where the edited child in Sandel is pre-set for certain outcomes, so Mintz et al. worry that the edited person will have their actions controlled by external factors where their 'autonomous decision making' is reduced, a violation of Kantian autonomy (2018). Granted, the embryo cannot act as an individual and so is dependent on the actions of their would-be parents to consider their interests which, according to Mintz et al., are to have their genetic integrity retained.

There are some issues to consider. Firstly, the assumption that traits must be protected, which infers adherence to the natural lottery, appears to absolve a society from blame if a preventable genetic disease occurs that affects the autonomy of the person or where capabilities are lacking. It is easy to say that there are traits that ought to be passed on, but there is a silence on traits that ought not be passed on and Mintz et al. would object to my capabilities index for mining the potential genetic conditions against their impact on the individual (as would Sandel and Habermas).

Secondly, ‘intrinsic’ or not, embryos do not have rights over the parents to necessarily force restraint on an action that is not intended to harm. Thirdly, the terms of autonomy are not absolute, thus even if there were ‘evolving intrinsic rights’ it still would not stop a successful petition to the court to permit certain actions for the protection of the would-be child (which may include GI in the future) because the autonomy of the parents should be greater than that of the foetus, and in many cases the child. For example, in *NHS Trust v Child B and Mr and Mrs B* the High Court argued on behalf of the best interests of the child to receive blood transfusions over the religious objections of the parents. The Court retained the right to consent for treatment on behalf of the child.

Lastly, Mintz et al. put to much stock in the absolute value of Kant’s approach. Whilst Mintz et al. concede that Kant’s vision did not include the embryo they still paraphrase Schroeder’s critique of Kant that ‘[Kant’s] notion of human dignity demands respect for every human life extending to the life of the unborn to the embryo’ and still conflate the embryo with a living person (2018). However, Schroeder also warns against a reliance on Kant because his view on dignity is vague and holds a contradiction between the ‘universal inviolability of dignity and the conferment of rights’, as we have seen with the contrast between the constraint and empowerment view (Schroeder, 2010).

## 8. Summary

Between the two forms of dignity, it is hard to justify RBAI on the original grounds of the right, no less because it could promote unscientific judgements that could unduly bound a society and individuals but also because the basis of rights, conferment through dignity poses more questions than it answers.

As argued in the analysis of the terms of dignity in human rights there ought to be space for a right to stand on its own value and strength. For example, it is wrong to torture because no individual would willingly want it done for them



and the aim for torture is not a legitimate one because of the means it undertaken for its end. The conflict for RBAI is between how the underpinning Freedom of Conscience should be understood and how dignity should be understood.

Freedom of Conscience, if understood to allow the individual to make their choices freely and understand them and themselves, relates to the use of the Freedom, rather than the existence of the Freedom. As such, innate dignity is not compatible with this formation of the right (or any formation where bioethics are concerned) no less because it would legislate when (and what) a person has 'conscience', in the context of the freedom. But also, because it presupposes that our dignity is transferred through our genes, which puts several present-day decisions in jeopardy, and that we can edit out the 'true' conscience of the individual as understood between  $t1$  and  $t2$ . This would be an erroneous claim as it offers too much power to the genes over us and ignores how the human operates in the world, not only an ability to make a choice for themselves (and for others) but build upon what they must cultivate their own identity.

The Freedom of Conscience as an element that an individual could use has slightly more value as it incurs values of autonomy and self-determination. Whilst it is impossible to legislate that an individual is born 'as is', as the 'is' is undefined, it is possible to legislate against intended incursions between  $t1$  and  $t2$ . However, dignity as autonomy and Freedom of Conscience are not the right avenues for this for it would reduce the possibilities to defend the interest of the future person, which is to have and use autonomy for their own interests. Interestingly, the Freedom relates to when an external body tries to determine how an individual uses the freedom, not how they understand it or are given it. Those born with a genome, 'natural' or not will have the ability to have and understand the freedom despite the many changes to the epigenome and genetic expression causes by a multitude of factors that individual will have.

## 9. Conclusion

The premise for RBAI was that GI has 'no moral purpose'. I have shown in earnest that GI has a value within a right originally used to justify the restrictions from RBAI – the Freedom of Conscience. Where Habermas argued that the individual will lose the ability to be self-critical and Sandel argued that there individual will have reduced natural 'gifts', I have argued that GI would not reduce the individual to a pre-determined 'doing' who is only their genes and

cannot think of any other aspect of their being. Rather, I have argued that GI could protect autonomy and opportunities and lead to a fairer future with a legitimate aim for GI assessed against the capabilities that the average person ought to have. As such, to protect these capabilities we can reduce the natural lottery to only an aspiration and embrace the reality that many will be losers through the natural lottery, and not the moral winners Sandel predicts. The utilisation of a ‘capabilities index’ would intercede RBAI and recognise that there is ‘no moral purpose’ to hold on to antiquated views of genetic integrity and recognise that a resultant individual, with the tools to participate, will have the freedom, criticality, and abilities that all individuals ought to have.

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