# (Re)producing Identities: The Assumptions in (non)Identity-Affecting Debates

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ABSTRACT

Advances in procreative technologies can entail changes on a number of levels: changing scientific realities but also changing ethical considerations, and changes to the concepts they use or assumptions that some ethical arguments rely upon. One such case has been how the move from the idea of selection to the idea of gene editing can affect arguments around what it is meant to benefit or harm the future offspring. With the help of Ying-Qi Liaw's recent framework (2024), as well as insights from Rosemarie Garland-Thomson (2019), we question the assumptions of 'identity' and 'disability' that are often used in 'person-affecting identity preserving (gene editing)' versus 'non-person affecting identity changing (selection)' debates (McMahan & Savulescu 2023). In so doing, we recognise that there is an additional 'person-affecting, yet identity changing' category emerging, when the trait changed or corrected is itself definitive of the identity in important respects. From this, we also explore how such debates have an echo of genetic determinism about them, and the appreciation of our social, environmental identity makes for a much more complex discussion than such debates initially suggest. Consequentially, we suggest moving beyond the narrow confines of such debates to one about the ways identities can be seen to be generated in positive (or negative) ways, rather than a concern about whether some identities are preserved or changed, for the better or worse.

## 1. Introduction

Advances in procreative technologies can entail changes on a number of levels: scientific realities but also ethical considerations, and the concepts they use or assumptions some ethical arguments rely upon. One such case has been how the

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move from the *idea of selection* to the *idea of gene editing* can affect arguments around what it is meant in terms of benefiting or harming the future offspring. Some arguments would say that when a pre-person or embryo is selected, the resulting future person cannot, by the act of selection, be benefitted or harmed given their alternative is non-existence (i.e. not a worse or better off alternative possibility). Such arguments are generally qualified so that a fate worse than death or, to say the same thing, a fate worse than non-existence is still to be avoided. Apart from this outlier, the general view is that one cannot be harmed or benefitted in this case in – what is often considered – the strongest sense: in person-affecting terms. As noted by Derick Parfit (1984), this is not the only form of harm or benefit that can be conceptualized. Changing the environment for the better now – to the degree it is likely required to seriously address climate change – will dramatically affect the existing social order, and ongoing social relations and interactions (including the 'who' and the 'when' in reproductive interactions), to such a degree that it is most likely that entirely different people will be born a few generations hence. Like selection, whatever the positive (or negative) changes that their ancestors made for the betterment of the environment, the future people would not have existed otherwise and – good or bad – their situation would not be harmed or benefitted in *person affecting* terms. This would seem to undercut many such cases where it clearly seems *better for people* in one scenario compared to the other. There is, Parfit and others would contend, an impersonal harm avoided, or impersonal benefit achieved. However, in many debates, there still seems 'something' stronger about benefit or harm in 'person-affecting' terms. This intuition that there is 'some difference' has motivated explorations in the context of reproductive technologies – comparing cases of selection and impersonal considerations, with gene-editing and person-affecting considerations. The sense of *something* stronger underlying person-affecting versus non-person affecting or impersonal – in this context – has motivated the likes of McMahan and Savulescu(2023) as well as Feeney and Rakić (2021) to explore how such a distinction impacts upon questions of harm and benefit in the reproductive context. In both cases, such discussions have used the example of disability as a case study or scenario to explore such questions in the comparison of ideas of selection and those of gene editing.

In this paper, we will first assess the forms of identity that are used in such discussions with the aid of the recent framework of Ying-Qi Liaw (2024). Secondly, we will explore the idea of disability that is also assumed in such discussions, exemplified by the insights from Rosemarie Garland-Thomson (2019)

and Boardman (2014; 2020; Boardman& Thomas, 2023). Such insights give rise to the view of disability itself as identify-defining which suggests the presence of an additional coherent category to the person-affecting identity preserving (gene editing) and non-*person affecting* identity changing (selection) categories. There seems to be a form of person-affecting, yet identity changing arising, when the trait changed or corrected is itself definitive of the entire identity, or at least in the ways it is considered important or crucial (gene editing in some cases of disability where the disability itself is important to identity). There will be some criticism of how this third category could be viewed as an extended social identity, or narrative, category that is used to make 'identity-preserving' decisions back at the genetic/biological decision-making context, and before any such social or narrative identity is ever formed (to be preserved in the first place). We tend to agree with this criticism, but we also support a greater appreciation of this disability perspective over 'what is often simply assumed to be a problematic disability' and this additional category may still be useful with a similar sense that there is also 'something' important captured by it. Finally, this paper outlines how this extended social or narrative identity touches upon an argument that many such *person affecting* versus non-*person affecting* debates have been overly genetic or biology-based, due to an echo of genetic determinism, long dismissed in the science, but lingering in some normative discussions on genetic interventions (Feeney 2019). Avoiding such misconceptions, it becomes clearer that the context of such identity-based and person-affecting harms (or benefits) misses how there are many more, complex and messy examples of how our identities are changed by many environmental factors as well as genetic and reproductive factors. We therefore hold that the broader (non)identity discussion – including McMahan & Savulescu and in the spirit of Liaw et al's framework –should be as much about generating identities as it is about preserving identities or changing identities.

## 2. Background

In the recent paper by McMahan and Savulescu (2023), they argue that there is, despite the risks, a moral reason to prefer genome editing an embryo rather than embryo selection, particularly in cases to avoid harm. This is because genome editing, they argue, would be better for the person who would develop from the edited embryo, whereas embryo selection is never better for the person who develops from the selected embryo. In the latter case, the person developing from

the selected embryo, whether or not there is a state of harm, could not have otherwise existed. However, for the person who developed from the edited embryo, there is a sense that they have benefitted by any edit that would have avoided such a state of harm. They emphasize this argument by referring to the case of deafness as a 'normally disadvantageous' trait that can be allowed to happen (by selection), or edited out of, or edited into, an embryo with such a trait (McMahan & Savulescu, 2023). Overall, their argument revolves around two things. Firstly, the concept of identity and how identity can be preserved or not, depending on the *person affecting* or non-*person affecting* technology used (i.e. gene-editing or selection). Secondly, these discussions have extremely high importance for the issue of disability – and the messaging that has traditionally being criticized with technologies that are aimed at reducing the incidence of disability. Such interventions as abortion and preimplantation genetic diagnosis (PGD) with selection have been charged with the expressivist message that it is better to remove disabled persons from existence. This 'expressivist objection' (EO), initially outlined by Buchanan (1996), is a view that believes that technology aimed to 'correct, ameliorate or prevent' disability presupposes and suggests a negative valuation of disabled people's lives. While Parens and Asch (2000) considered the objection in the context of prenatal screening, Boardman and Thomas (2023) note how it has continuously adapted to follow the technologies' developments from testing to germline genome editing. In whatever form the expressivist objection arises, as Parens and Asch (2000) argue, when the (future) person is reduced to the identification of a disability or specific impairment, a message that 'there is no need to find out about the rest' is conveyed. This is particularly stark in the context of reproductive decision-making. However, following the above reasoning and change in context from the impersonal framing of 'selection' to the person-affecting framing of 'gene editing', there is the potential alternative image or message – that this is the removal (or correction) of a disability or specific impairment, and not the removal of the *person* with that disability or impairment. In other words, the embryo would not be removed, but – *in a manner of speaking* – 'treated' with the disabling trait corrected[**]. In this case, the response would be that it is more in line with traditional

[**]It is perhaps more accurate to use the term 'prevention' here, rather than 'treatment', as this is a point before the person and before the disability would exist. However, this may then be confused with the form of 'prevention' in selection contexts. Hence, 'treatment' is used here as it reasonably captures the difference between selection/prevention and gene-editing/treatment contexts.

post-birth curing of injuries, to hearing, sight, mobility, and so on, that would otherwise cause a disability, as opposed to the previous message of removing disabled people. There are a number of responses to this line of reasoning. For instance, reflecting the point by Sparrow (2022), there is a persistence of the selection context in reality because there would likely be two selection processes involved in the gene editing intervention context – at the start, in the generation and selection of the optimal embryo(s) to intervene upon (which would not be selected otherwise) to the perhaps also likely intervention on more than one embryo, with subsequent selective implantation, with another modified embryo reserved in case this birth turned out to be unsuccessful. Another response may look to how the disability itself is considered by some to be the very core identity and, so the line of reasoning would seem to suggest, to remove even this, is to remove what is important about that person's identity (Rosemarie Garland-Thomson, 2019; Boardman, 2014; Boardman & Thomas, 2023). Yet another response might point to the fact that a number of people who are disabled would view this entire focus to be misguided because they value that biological trait that is considered a disability, or consider it a part of the normal variation of human capabilities and characteristics, while arguing that it would be the social barriers – against some of that variation of capabilities and characteristics – that is doing the disabling (e.g. neither wheelchair ramps nor stairs are natural, yet choosing one over the other would disable some compared to others) (ibid). Building on the discussion of identity formation through both genetic and environmental factors, it is crucial to keep in mind the diversity of parents' and communities' perspectives on genetic traits. As noted by Feeney and Rakić (2021), there is a subjective quality of life that is underacknowledged by McMahan and Savulescu (2023). For instance, some deaf parents prefer their child to be deaf, others don't. Some people say that their love for a child with Down syndrome is so profound that they would not like to have a "normal" child. Others would be tremendously happy not to have a child with Down syndrome. Some such views will be examined in more detail below (Boardman 2014, Boardman and Thomas, 2023).

## 3. Identity Concept in Human Genome Editing Debates

Debates about human genome editing (HGE) often invoke the concept of identity. However, academics have different emphases on identity and refer to diverse philosophical traditions. Liaw (2024) conducts a detailed analysis of the

different interpretations of the concept of 'identity' in the literature on human genome editing. She fundamentally distinguishes between numerical identity (including identity-over-possible-worlds and identity-over-time), qualitative identity, genetic identity, and narrative identity.

One form of numerical identity, identity-over-possible-worlds (p. 124), pertains to a specific line of discussion initiated by Derek Parfit's book "Reasons and Persons" (1984). The non-identity case discussed in it implies that our identity depends on the time and circumstances of our conception. For example, a woman delaying pregnancy for two months on a doctor's advice does not benefit the child she could have conceived without this advice. The child conceived via following medical advice is a different individual, resulting from the different sperm and egg. From this perspective, an embryo created through HGE or other technologies involving in vitro fertilization is very likely not identical to an embryo that could have been conceived without these technologies.

The second form of numerical identity, identity-over-time (p. 125), raises the question of the subject's persistence despite changing. In the context of HGE, this refers to evaluating the extent of genetic changes – whether they create a new subject or not. The biological view of the problem suggests criteria such as the preservation of cellular functions or epigenetic continuity. HGE in its current form usually does not involve radical changes and is recognized as meeting these biological criteria of identity-over-time.

Genetic and genomic identity also refer to a biological perspective and "entails the structural makeup, functions, or roles of the genes" (p. 123). These concepts are often applied to the population genomics capturing the specificity and diversity of humanity as a biological species. At the individual level, these terms indicate the impermissibility of intentional interventions in human hereditary traits (Liaw et al., 2021: pp. 408-409). The focus on unique characteristics aligns this concept with qualitative identity, which refers to the traits allowing the recognition of an individual. From the qualitative point of view, clones are identical while they are numerically distinct (p. 126).

Numerical and qualitative identity are more common in texts of the analytic tradition; genomic identity is mainly a term from international documents on HGE ethics. The concept of narrative identity generally appears in psychological, phenomenological studies, and cultural anthropology. It does not directly refer to biological processes that determine the unique traits of an individual - that are subject to HGE. However, Liaw notes that knowing one was born through the application of HGE may affect an individual's self-conception and

reproductive plans (p. 127). However, Liaw only briefly mentions the intersubjective, relational nature of narrative identity. She points out the possible social influence of media narratives about HGE and mitochondrial donation on individuals born via these technologies.

Meanwhile, the possibility of HGE already influences the group narratives of some communities, thus affecting the self-conception of their members and their expectations of social inclusion and diversity. Liaw prefaces her paper on identity with a commitment to the call by Almeida and Ranisch (2022) to continuously engage with the public on value-laden concepts such as "human diversity." The elimination of individual genetic traits through HGE is a concern not only from the perspective of humanity's genomic diversity. Such implications of HGE are a sensitive topic for many disabled communities, and therefore for issues of social diversity. For example, people with inherited retinal conditions consider the elimination of relevant genetic traits through HGE comparable to eugenic programs (Hoffman-Andrews et al., 2019). Members of this community are also concerned about reduced public attention to eliminating barriers for blind people in case HGE becomes widely available. Both their concerns – neo-eugenics and reduced support – connect HGE with the issue of identity through belonging to a social group.

Tom Shakespeare, a sociologist and bioethicist known for his work on disability rights, advanced the topic of social identity in the 1990s and 2000s. He noted that the identity of a disabled person arises through association with a non-dominant social group in a discriminatory society. The social model of disability he advocates rejects individualistic and over-medicalized approaches. This model proposes shifting the focus from individual impairment to the social construction of disability (Shakespeare, 2006). Thus, an individual's relationship to collective narratives about disabilities determines their identity. Collective narratives are reproduced in disabled communities and sustain them. Such narratives also map external attitudes towards disability in the wider society and sometimes respond to it (Shakespeare, 1996; Estreich, 2019; Bonner, 2023). The concerns of people with inherited retinal conditions are related to HGE's potential contribution to societal understanding of their conditions. HGE may not change the self-conception of community members but can influence their identity by altering their collective narratives. Reproductive technologies can exacerbate the gap between their experience and external understanding of their conditions and genetic traits in the wider society.

These debates, which explore the role of collective narratives in shaping identity, offer a new perspective on two major positions about personal identity and its persistence: animalism and the psychological perspective, which traces back to John Locke (Olson, 1994). Animalism asserts that the human person is numerically identical to the human animal—that is, the organism belonging to the species Homo sapiens. The second perspective views the human person as a thinking being, whose persistence is ensured by memory. In this sense, discussions about genomic identity tend to align with the animalist approach, while questions of narrative identity are more closely related to the neo-Lockean views. However, the animalist approach can also accommodate the variability of the human person over time and their dependence on interpersonal relationships. Immunology suggests that the boundaries of the human organism are difficult to define; instead, it leads us to think about the "self" in terms of spatial and temporal continuity (Pradeu, 2011). Such continuity includes different entities and therefore identity might be attributed not to a single agent, but to an ecosystem comprising living human cells, dead tissues, and the microbiome. These components change over time: interhuman interactions can cause microbiome changes, which in turn influence a person's mental states (Huneman, 2020).

Thus, animalism intersects with the psychological approach. Yet, it fails to integrate the social significance of individual traits, which can be crucial for a person's understanding of their identity. Collective and societal dimensions of narrative identity are also frequently overlooked in the neo-Lockean perspective, despite their compatibility and, moreover, their importance for psychological account of identity. Therefore, our argument emphasizing the social dimension of identity is generally compatible with both the perspectives of animalism and psychology, but shifts their emphasis from the individual to the collective domain.

## 4. (Non)identity and the Moral Difference between Genome Editing and Embryo Selection

Liaw proposes integrating four types of identity into a multi-faceted concept of identity to use in discussions about HGE. This concept might be further enriched with a social perspective, stemming from collective narratives on disability. However, ethical discussions about HGE often focus on a single dimension

of identity, such as numerical identity. This understanding of identity grounds McMahan and Savulescu's (2023) argument that gene editing is a morally superior method for preventing genetic disorders compared to embryo selection. Their main point is that gene editing is better for the individual who would develop from the edited embryo, whereas embryo selection does not make life better or worse for anyone. Two key points support the 'better for someone' argument: First, the emergence of an individual who maintains numerical identity precedes gene editing. Second, editing does not disrupt the numerical identity of the embryo. Based on the multi-faceted concept of identity, both of these assumptions can be questioned.

As for the first assumption, McMahan and Savulescu (2023) emphasize, "if we begin to exist before gene editing might be done, then it is clear that the editing can be better or worse for the person who may develop from the embryo" (p.11). To test this condition, let us consider two scenarios. In the first, selected gametes undergo in vitro fertilization, and the resulting embryo is then genetically edited. In the second, the same selected gametes are first edited (altering the same nucleotide sequence), and then in vitro fertilization is performed. The embryos resulting from both scenarios have the same genome; they are qualitatively and numerically identical, originating from the same gametes. Knowledge of having undergone genome editing can equally affect individual self-conception and a sense of belonging to social groups, such as those with disabilities. From the perspective of the multi-faceted concept of identity, the embryos in both scenarios are identical. However, the criterion of the pre-existence of 'someone' who benefits from editing is met only in the first case. This suggests that the issue of identity in HGE debates is not limited to numerical identity. Even within this dimension, confusion can arise between identity-over-possible-worlds and identity-over-time.

Bolstering the second assumption, McMahan and Savulescu (2023) argue that HGE can be both identity-determining and identity-preserving. They classify interventions that result in only slight changes, such as a minor alteration in eye colour, as identity-preserving (p.11). In contrast, identity-determining genome editing implies more significant biological changes, such as those that "change the embryo's biological sex" (p.11). They assert that "when gene editing is identity-determining, it is relevantly like embryo selection in that it causes one person to come into existence rather than another" (p.11). However, the distinctions between identity-over-possible-worlds and identity-over-time allow us to differentiate between selection and editing. Even major genomic changes,

like altering the embryo's biological sex, still involve epigenetic continuity and the preservation of cellular functions. From the identity-over-time perspective, this means we have the same numerical embryo as before the editing. In contrast, embryo selection, even for the most minor traits, implies numerical non-identity of embryos selected in different possible worlds.

However, if we adopt the multi-faceted concept of identity and move beyond numerical identity, even editing the minor trait can shift the narrative identity. For example, knowledge of genome editing leading to a "slight change in the shade of the eye colour" can affect an individual's self-conception. The motives behind this intervention, such as enhancing resemblance to a famous grandmother, might influence narrative identity, leading to an intensified comparison of one's life story with her biography. Similarly, knowledge of any method of eliminating genetic traits associated with disability – through embryo or gamete genome editing; embryo, or gamete selection – can influence an individual narrative identity and their relationship with parents belonging to the disabled community.

While these considerations focus on the identity-related implications of human genome editing, the broader ethical debate addresses the complexities of causing benefit versus preventing harm in such interventions. For instance, McMahan and Savulescu (2023) attempt to show that the ethical benefit of a genetic intervention or an induced abortion by showing the lack of harm caused by one of them or by both. This position has its background in the more than a decade old debate on whether it is easier to cause benefit or harm. Persson and Savulescu (2011) asserted the former, exemplifying it with a deranged truck driver who drives his vehicle into a group of fifty innocent people. This is easier than causing benefit of the same magnitude to fifty people. Objections to this argument included the fact that preventing a lunatic from carrying out his act amounts to causing benefit to a large number of people whose lives have been saved by someone who prevented the truck driver to realize his intention. Persson and Savulescu (2011) argue, however, that it is very difficult to find oneself in a situation to prevent a truck driver who has decided to opt for a murderous rampage, from carrying out the monstrosity he intends. Hence, preventing major harm remains difficult as it is not very realistic. As noted above, notions of harm and benefit can be subjective, characterizing the personal identity of the

holder of these beliefs, or the identity of a particular community.[††] While there are many differences in the context, the question over how one can create more benefit than harm with new genomics technologies in the context of assisted reproduction, is one that is more often assumed by some in the medical fields, without adequate appreciation of how the same actions could create even more harm. This is a question that is intertwined with the question of identity.

## 5. Beyond the traditional (non)identity (non)affecting distinction?

This discussion of the more complex understandings of identity, or rather identities, is useful in understanding what seems to be an apparently fundamental disagreement in the impact of the idea of genome editing compared to the idea of selection for persons with disabilities. One challenge to the application of reproductive technologies to the avoidance of disabilities (via PGD) has traditionally been particularly summed up by the aforementioned expressivist argument, stating that the selection out of disability sends out the negative and damaging message: that the world would be a better place if people with disabilities did not exist. Adopting the traditional distinction – person-affecting identity preserving (gene editing) and non-*person affecting* identity changing (selection) – some can see the move from a genetic selection (PGD) context to a genome editing context to be potentially deeply significant–at least in terms of this expressivist message (Feeney & Rakić, 2021). Felicity Boardman observes this potential change of messaging when she notes:

> [by the] preservation of the life of the embryo (that would otherwise be disabled), and eradication only of the disabling trait, germline genome editing indeed appears to neatly sidestep one of the most critical social and ethical concerns levelled at current methods of genetic disease amelioration: that the disabling trait is considered more significant than the life of the embryo or foetus (Boardman, 2020: p. 125).

On the other hand, Iñigo de Miguel Beriain (2020) does feel this change to be deeply significant, when he states that:

> unlike preimplantation genetic diagnosis (PGD), [germline gene editing] does

[††]The question remains regarding why can't Persson and Savulescu prove their stance that causing benefit is relatively easy in a direct, straightforward manner - without resorting to invoking the thought experiment that proves the relative difficulty of causing harm, and applying this as an analogy in order to prove that causing benefit is relatively easy?

> not send the message that not living at all is preferable to living with a concrete genetic trait that determines a concrete condition because the use of PGD tools results in the unavoidable process of destroying embryos with traits that will trigger concrete pathologies [...]. In contrast, GGE does not result in the destruction of embryos, but instead alters the expression of such traits, to avoid disease occurrence. This process creates a totally different scenario, resulting in this intervention, sending an alternative and totally different message that living without the condition is better than living with it, which appears to be an acceptable conclusion for everyone. Thus, GGE appears to be a perfectly acceptable and necessary method for addressing the issues posed by disabling genetic diseases when identified in in vitro embryos (p. 241).

Like Boardman and de Miguel Beriain, Jackie Leach Scully (2019) highlights how Prenatal Diagnosis (PND) and Preimplantation Genetic Diagnosis can be considered 'eliminatory' while Genome Editing, by contrast, can be considered 'therapeutic' or 'restorative', at least by some. She notes that they are "the class of interventions that is harder to criticize: ones aiming "simply" at the removal of disability", and as such, she acknowledges that others could view that a "repair of the genome is morally more acceptable to most people than the eliminatory approaches of PND and PGD, so all other things being equal, uptake of gene editing is likely to be higher" (2019: p. 156). Boardman notes how a simplistic understanding of the expressivist objection had already been criticised by Malek (2010) who argues that it should distinguish the disvalue of a disability from any disvalue of a person who happened to have such a disability (Boardman, 2023). This change of context would seem, on the face of it, to make this distinction stronger. So, for the moment, we might provisionally propose that there seems – to heavily qualify the stronger position taken by de Miguel Beriain above - a *potential* change *of some significance*, especially in terms of the expressivist messaging that may portray.

One reason for heavily qualifying such potential significance is, to recall an earlier point, that some might view the entire assumption that a disability – or rather any underlying genetic component of a given trait associated with disability – is a necessarily and intrinsically negative occurrence is to be misguided in the first place. Felicity Boardman (2020) highlights the use of the term 'Deaf gain' to describe cognitive to cultural benefits from 'Deaf ways of being in the world', and draws

> "attention to the possibility of disability being an enriching experience, both at the individual and societal level" (p. 246). More broadly, Scully argues that "it is

> a mistake to think of impairment as never anything but an unambiguous harm and therefore it is not always obviously right to use technologies like gene editing with the aim of removing bodily differences" (2019:p. 157).‡‡

This all relates back to the more fundamental assumptions over what exactly is meant by 'disability' or to be 'disabled' (Wendell, 1989). The biomedical and genetic approaches above may be misguided in terms of the primary cause of disability and, therefore, their solutions or remedies are also misguided (Barnes, 2016). Such approaches may naturally (and logically) align themselves with the medical model of disability that give priority to the view that disability is "a personal, medical problem, requiring but an individualized medical solution; that people who have disabilities face no 'group' problem caused by society" (Areheart, 2008: p. 186). By contrast to the medical model of disability, the social model sees disability "as a deviation from society's construction of corporeal normality [consisting] largely of encounters with the many barriers erected by society – physical, institutional, and attitudinal – that inhibit full participation in mainstream life" (Areheart, 2008: p. 188).

The social model account of disability can be well exemplified in the words of Rosemarie Garland-Thomson (2019) who highlights how she, and others with congenital disabilities "have flourished, not in spite of our disabilities, but rather with our disabilities" (p.19). This claim, she continues "sits uneasily with modern medicine's framing of disease, disability, and anomaly" (ibid). While Garland-Thomson accepts that there are indeed limitations due to various conditions, such as blindness and deafness, she views such limitations as existing primarily due to the way the built environment and the social world in general is designed for those without such conditions. On one hand, this seems correct, at least to some degree. As noted above, neither ramps nor stairs are natural and both would be needed to get to the second floor of any building, *for anyone*. Yet

‡‡Scully (in Parens & Johnston eds. Human Flourishing in an Age of Gene Editing. OUP 2019) moves the focus to one of (genetic) control – control as an aspect of the unquestioned values in contemporary world linked to self-determination and autonomy – resting on prioritized ideas of the individual, autonomous, unencumbered self. Similar sentiments are shared by Wendell (1989). Scully notes that this view has been criticized by feminist and communitarian viewpoints, in favour of a more relational model of personhood – relational ties to others of responsibility and dependence as not compromising but actually being part of the real conditions of real self-determination. She highlights the need for wider empirical work on bioethics – not just scientists but wider expertise (Note: the empirical work she cites is before CRISPR/not on gene editing). She holds that there is an ambiguous value on expanded choice compared to a value of acceptance.

choosing one over the other would disable some compared to others. Nevertheless, it may be too strong to view such limitations as simply or entirely due to the social environment, even if they were to a significant functional degree. Being able to see and hear opens up a world of music, views of sunsets and a flexibility and adaptability to function in a wider variety of environments, from those adapted, to the many areas unlikely ever to be fully adapted (e.g. old towns, remote villages, etc) or those beyond the detailed social design of humans (e.g. the open countryside). A plausible stance may seem to be some mix of both models – the relative weighting depending on the particular disability, or degree of disability (Hull, 1998). In recent years, the focus has moved increasingly toward biopsychosocial models of disability within disability studies (Boardman 2023). This is a promising approach, albeit with a potential charge that it may just relocate the source of disagreement from 'medical model' versus 'social model' to 'how much medical model' and 'how much social model'. Despite this lack of specification (or perhaps because of it), one can see it as potentially acceptable to Garland-Thomson where she notes that:

> "[t]o support some of the human variations we think of as genetic disorder, disease, anomaly, or disability does not preclude appropriate interventions – sometimes medical, sometimes social – that ameliorate pain and suffering or promote human functioning and flourishing. Supporting disability in this way also includes using technology as a bridge between flesh and world. A call for such a moral ecosystem is not status quo bias, passive acceptance, moral timidity, or resistance to imagining something better than the present circumstances. Instead, it is a caution against an aggressive normalization imperative that eliminates rather than accommodates" (2019: p.24)

It might be noted that this use of 'eliminates' by Garland-Thomson seems more suitable to the idea of selection rather than the context of genome editing. However, her use of this term in the context of CRISPR-related germline interventions suggests a different understanding of what constitutes the relevant source of identity in the move from a non-person affecting identity changing (selection) context to a person-*affecting identity* preserving (gene editing) context, that is seen by de Miguel Beriain, Savulescu and others to be deeply significant.

This can be seen where Garland-Thomson (2019: p18) notes how germline interventions are a "pruning of human variation at the genetic level [that] proceeds with little consideration of our perspectives as people who live out these genetic narratives". She also notes that others, such as Jürgen Habermas, flourished not in spite of their lived experience of disability, but because of it. She

argues how the differences (whether blindness or a cleft palate) gave rise to experiences that would not have arisen otherwise and that contributed to individuality and a unique life of flourishing (2019: p.21). Importantly, she notes that such differences were integral to one's being – a distinct life through a particular body (ibid). What this perspective highlights is that even if one could, through genome editing, avoid the destruction of embryos, but rather alter the expression of such 'disabling traits', this would be still be an eliminatory framing in terms of what effectively is the source of the identity that matters for some, such as Garland-Thomson – that is not just the embryo, or the 'rest of the self", but that 'disabling trait' too. In keeping with the narrative understanding of Liaw (2024), the disability itself – as integral to one's being – seems as identify-defining, in the way that matters, at least for some. Similar sentiments are expressed by some of the participants in various empirical studies outlined by Boardman (2014) and Boardman and Thomas (2023). Such studies show a diverse range of alignment with how integral the disability or impairment is to the sense of self, identity of oneself or of one's family member, including factors such as age of onset, type of impairment or disability and so on (ibid). What seems to emerge is a distinct additional category beyond the familiar person-affecting identity preserving (gene editing) and non-*person affecting* identity changing (selection) outlined above: that is a form of person-affecting, yet identity changing arising, when the trait changed or corrected is itself definitive of the entire identity in the important respects. For precision, it would be useful to illustrate it as follows:

1. Non-person-affecting/impersonal and identity changing (the idea of selection context): embryo Q which would have developed into future person Q+ is replaced with embryo P which then develops into future person P+.
   a) It is a process that changes the future person in its genetic entirety.
   b) This 'entire genetic' change is to change the identity of the future person in all relevant respects.
   c) The future person P+ has no relationship (in terms of identity) with embryo Q.

2. Person-affecting and identity preserving(the idea of gene editing context): embryo Q which would have developed into future person Q+ is edited using CRISPR-Cas9 to change a specific trait, leaving the rest of embryo Q unaffected and then develops into future person Q+.

a) It is a process that preserves the future person *almost* in its genetic entirety, bar some genetic changes.
b) This 'preserving of the almost entirety of the genetic material' is to preserve the identity of the future person in almost all (or at least most and sufficient) relevant respects.
c) The future person Q+ has a sufficient relationship (in terms of identity) with embryo Q.

3. Person-affecting and identity changing (the idea of gene editing context):embryo Q which would have developed into future person Q+ is edited using CRISPR-Cas9 to change a specific trait *connected to a specific disability*, leaving the rest of embryo Q unaffected and then develops into future person Q+, *but without that specific disability.*
   a) It is a process that preserves the future person almost in its genetic entirety, bar some genetic changes.
   b) This 'preserving of the almost entirety of the genetic material' is *not* to preserve the identity of the future person in *almost all* nor the *most and sufficient* relevant respects (because the specific trait connected to a specific disability is removed).
   c) The future person Q+ does not have a sufficient relationship (in terms of identity that matters) with embryo Q, *without that specific disability.*

In short, while scenario 3, is akin to scenario 2, (person-affecting) in most respects, especially the process and crucially in terms of identity as considered as relevant in such debates of McMahan and Savulescu and others, it all depends on what is considered crucial in terms of identity. Others (such as Garland-Thomson) may view scenario 3, more akin to scenario 1, (identity-changing) in the respects that matter – that is, in terms of what is crucial about a concept of identity that counts.

Such an additional category, insofar as it seems to emerge from this discussion, can be criticized. Firstly, there seems a tension here with the concept of the expressivist objection noted earlier in the paper. As outlined by Parens and Asch (2000), a key aspect of this objection is the reduction of the entire future person's identity to that particular (disabling and disfavoured) trait, and ignoring all the other aspects of that future person. On this occasion, the presence of the disabling, but favoured trait is that which is an intrinsic, irreplaceable aspect of that future person's identity. On the face of it, the only difference seems to be that it is more acceptable to conflate the disability with the person's identity if it

is favoured, but not if it is disfavoured. Moreover, this narrative form of identity is something that emerges ex post, and it is problematic to use this to make decisions for a future person ex ante. The adult individual assesses whether changing a trait has positively affected their identity. The value of some identities may also depend, at least in part, on the presence in some location of a community of people declaring their specific identity due to inherited traits. For example, in location A, the presence or absence of Marfan syndrome affects identity because there is a strong community of people with this syndrome, declaring their distinctiveness and having political representation. In location B, there is no such community, and the syndrome does not create such a social identity. Boardman and Thomas (2023) outline a diverse range of responses to the relationship between identity, impairment and disability, particularly reflecting a range of perspectives from persons or families affected, as well as highlighting how such questions are a source of ongoing discussion and debate. In this paper, we only wish to bring some such insights into the more insulated philosophical debates on identity and non-identity, particularly where disability is involved.

However, at this point, it increasingly feels less like we are discussing identities that can be simply preserved or changed by the purported change in context noted above – from selection to genome editing, and we are entering a much more complex, and fluid, context – more so than was even suggested by Liaw (2024). It is also a debate with a much broader focus, that not only occurs in the context of disability, but in the context of what makes us 'us'. In short, a broader, and perhaps more fundamental question, is on whether there is anything important about the bare 'genetic identity' in this, or any, context.

## 6. The charge of genetic determinism and the social non-identity problem

There is general acceptance that the genetic determinist picture is a gross misunderstanding because it unduly privileges the genetic part of who we are (Feeney 2019). When we talk about DNA, we are not talking about an actual 'person-in-waiting', but rather about one of the necessary (but not sufficient) factors that influence the resulting identity. Environmental influences are also similarly necessary (but not sufficient) for the resulting identity. These can be considered to be originating (naturally) from within the woman's body (e.g. in utero environment) or from the outside via the woman's body. This can bring in other environmental influences that are fully outside the woman's body, such as the disposition to smoke that can be correlated with, amongst other things the

expectant mother's education and income. In turn, these can be linked to society; its provision of education and its income structures.

Nevertheless, as has been argued elsewhere (Feeney 2019), there has been a continued reliance on misleading genetic essentialist assumptions by some important ethical approaches. This can be seen in most or all such familiar *person affecting* versus non-*person affecting* debates, in so far as they have been overly genetic or biology based. To highlight this, we refer to a previous exploration of the purported change of context from the idea of selection to the idea of genome editing (Feeney & Rakić, 2021) which was inspired by a case from the turn of the century where an American couple effectively selected for a deaf child (via sperm donor) named Gauvin (Feeney & Rakić, 2021)). Abstracting from the actual Gauvin case, we outlined the following routes (box 1) that the couple desiring a deaf child might have taken had it been possible for them to do so (Feeney & Rakić, 2021).

Box 1

Gauvin 1: Sharon and Candy go to an IVF clinic and, with the aid of artificial insemination by donor, create a number of embryos. They use PGD to select for an embryo that has the trait for deafness. This embryo turns out to be Gauvin.

Gauvin 2: Sharon is pregnant with an embryo or early-term foetus which has a hearing trait. She goes to a clinic that performs gene editing with CRISPR-Cas9. The embryo or foetus now has a trait for deafness. The embryo or foetus turns out to be Gauvin.

Gauvin 3: Sharon has just given birth to a baby boy that has the hearing trait. The obstetrician performs an immediate and painless surgery on the ear. The newborn is now deaf and is named Gauvin.

(From Feeney & Rakić, 2021)

These scenarios highlighted that how our moral intuitions and reactions may be affected by the presence or absence of person-affecting harm, versus impersonal harm (Feeney & Rakić, 2021). However, if one moves beyond the framework of an incorrect assumption of genetic determinism, the scenarios get less straightforward. In terms of DNA alone, the distinction between, for instance, Gauvin 1 and Gauvin 2 is still there, but it is less fully important than if DNA was the only influence. There may still be Gauvin 1 but in a weaker sense of being Gauvins 1.1, 1.2...1.x, where the first number signifies the genetic influences and the

latter number the environmental ones. Similarly, there will still be Gauvin 2 but in a weaker sense of being Gauvin 2.1, 2.2...2.x, and so on. Selection seems stark when presented as Gauvin 1 versus Gauvin 2, but may be less so if it is presented as Gauvin 1.5 versus Gauvin 2.3 versus Gauvin 1.3, assuming the view that the environment contributes as much as the genes do is accepted. This can also apply to the case of Gauvin 3 if we assume that this process of formation does not halt at the moment of birth. Once born, the environmental process continues to operate on Gauvin via the parental home and the social circumstances surrounding it. We (how we turn out) are not identical to the newborn babies we once were; it would be worrying if we were. We acquire who and what we are gradually, not only in terms of in vitro or in utero interventions, but after the point of birth in terms of social interventions, and after some time of external living existence.

Insofar as the non-identity problem goes, it is not necessarily unique to the context of new reproductive technology. Equivalent issues as the above can (to a great degree) be environmental in origin, and, as a large part of what is environmental for people is societal in origin (in whole or in part), then we are social in origin. The social distributions between people, assuming they are significant, already entail a distribution of people, with certain behaviours, personalities, abilities, and identities. This extension of the non-identity problem is not as unintuitive as it may appear. This is highlighted when we think of one of the misconceptions of cloning DNA as being seen to be the cloning of 'persons'. The misconception of cloning here is that it will replicate the original individual as opposed to the genetic material. Take the Hitler example. If genetic determinism was true, or genetic identity was sufficient, a danger exists that if some group with Nazi sympathies got Hitler's DNA and had the necessary means, they might clone Hitler and Hitler would once again pose a threat to Europe and the Jewish people. Although we would not be justified to blame the new Hitler for the old Hitler's crimes, there could be a utilitarian argument for arresting the new Hitler, or otherwise detain him. At the very least, we should automatically judge him to be antisemitic and a poor artist. Coming to this conclusion would be absurd. The less we cling to a genetic determinist stance, the more we see existing (and less morally problematic) environmental means as not only revealing or restricting a pre-existent identity, but as being co-authors of a developing identity. So, even if the new Hitler were likely to be a poor artist depending on genetic influences colour perception and other basic skills (influences for, not 'genetic skills'), this person, from within a different womb, upbringing, socio-

economic and cultural environment, and a different temporal existence, would be a different person; not Hitler. This is not just the 'time-dependence claim' where temporal differences entail different gametes (sperm and/or eggs) to come together and where such differences would entail a different person to exist. The claim in question is that, even if (somehow) the same gametes could later meet, the resulting person and the identity in question is different than it would otherwise be (due to the changes in the environment).

What we are can be traced back to our gametes. But it can also be traced back to our upbringing, our initial social class environment, our geographical location, our culture, our language, and so on (and so on). Looking at box 2 below, the non-identity problem and the problem of who is harmed is not simply genetic (1 below), but social as well. The more we move from a determinist view that Hitler's genetic material being cloned gives rise to Hitler (2 below), the more we move toward the social non-identity problem (3 below).

Box 2

| | |
|---|---|
| 1) Genetic Non-identity problem | $DNA^1 + Environment^1 = Hitler$<br>$DNA^2 + Environment^1 = Not\ Hitler$ |
| 2) Clone of Hitler problem | $DNA^1 + Environment^1 = Hitler$<br>$DNA^1 + Environment^2 = Hitler$ |
| 3) Social non-identity problem | $DNA^1 + Environment^1 = Hitler$<br>$DNA^1 + Environment^2 = Not\ Hitler$ |

If we move away from the simplistic genetic determinist view, we move from the naïve worry that cloning Hitler's DNA would give rise to a new Hitler identical in every substantial way to the first. Yet, in moving from this naïve worry, we are also unavoidably compelled to view environmental changes as identity-changing to a degree comparable to identity changes brought about by genetic selection.

It might be responded that there is not such a radical conclusion such as this. No matter what the environmental changes, no matter how radical they are, there is an important asymmetry between the changes from genetic selection and those of environmental influences; in the former, there is a numerically distinct individual, but in the latter the numerically same individual remains. But given what matters, is this numerical aspect sufficient? Unless we are to fall back to

genetic determinism, we cannot accord this much weight. Suppose a newly fertilized egg that was, in the normal course of events, to become John, was rather removed and frozen for four hundred years and implanted into the womb of the original, biological mother's great, great, great, (etc) grand-daughter. Would John be her great, great, great, (etc) uncle, or the future mother's son? The original DNA would be same. But the new 'mother' would have a vastly different diet, a uterine environment that may trigger a change in sexual preference , and would be the source of the proteins and other materials that would have gone into the construction of the cells. Beyond genetics and biology, the social role of 'mother' would add further complexity to this question. Whatever the answer would be (if there be one answer), it is not clear that the numerical distinctness of the original genetic material can be the source of a definitive answer either way. It may be more plausible to say that the original 'John' would not now exist and the degree of difference between this person and the original John would be the degree of 'son-ness' the new person has to the future person.

It might be replied that if, implausibly for the sake of argument, that it was a clean 50/50 split, then the environmental half is far more fractured than the genetic half – for example, schooling is responsible for 10%, culture for 15%, parental upbringing for 25%, etc. Changes to one half might be as important as the other half, but the environmental half can be changed in parts and not altogether, whereas selection rids the other half in one go. The focus on genetic therapy would answer the latter point by making piecemeal changes on the genetic half more comparable to the environmental half. But even in the case of selection (or radical gene therapy) it can be put that there could be cases where many aspects on the environmental half is problematic and could be in need of change. We highlight here that the proper appreciation of the formation of the person or human is intrinsically social and environmental in their identity, to the effect that there are many more, countless more, examples of how our identities are changed by many environmental factors as well as genetic and reproductive factors.

## 7. Conclusion

So we see that, broadly, debates have an echo of genetic determinism about them, and the appreciation of our social, environmental identity makes for a much more complex discussion than such debates initially suggest. Identity is shaped by a combination of genetic and environmental influences, both internal

(e.g., in utero environment) and external (e.g., socio-economic factors). Advances in procreative technologies can also entail changes to what is entailed by 'identity' on a number of levels: changing scientific realities but also changing ethical considerations, and changes to the concepts they use or assumptions that some ethical arguments rely upon. One such case has been how the move from the idea of selection to the idea of gene editing can affect arguments around what it is meant to benefit or harm the future offspring. With the help of the recent framework of Ying-Qi Liaw (2024), as well as insights from Rosemarie Garland-Thomson (2019), Boardman (2024), Boardman and Thomas (2023), and others, we questioned the assumptions of 'identity' and 'disability' that are often used in 'person-affecting identity preserving (gene editing)' versus 'non-person affecting identity changing (selection)' debates (McMahan & Savulescu 2023). In so doing, we recognised that there is an additional 'person-affecting, yet identity changing' category emerging, when the trait changed or corrected is itself definitive of the identity in important respects. While not without criticism, this category seems appropriate to capture – in the more philosophical debates – some important insights from those with disabilities where a rich literature exists.

In the end, we hold that the discussion about shifting from selection to genome editing, along with the accompanying questions regarding identity-preserving interventions (gene editing) versus identity-changing interventions (selection), and the proposed category of person-affecting yet identity-changing interventions (gene editing*), is as much about generating identities as it is about preserving or changing them. Consequentially, we suggest moving beyond the narrow confines of such debates to one about the ways identities can be seen to be generated in positive (or negative) ways, rather than a concern about whether some identities are preserved or changed, for the better or worse.

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REFERENCES

Almeida, M., & Ranisch, R. (2022). Beyond safety: mapping the ethical debate on heritable genome editing interventions. *Humanities and Social Sciences Communications*, 9(1), 1-14.

Areheart, B. A. (2008) "When Disability Isn't "Just Right": The Entrenchment of the Medical Model of Disability and the Goldilocks Dilemma," *Indiana Law Journal*: Vol. 83: 1(5). Available at: https://www.repository.law.indiana.edu/ilj/vol83/iss1/5).

Barnes, E. (2016) *The Minority Body: A Theory of Disability*. Oxford: Oxford University Press. doi:10.1093/acprof:oso/9780198732587.001.0001

Boardman, F., & Thomas, G. (2023). Expressivist objections to prenatal screening and testing: Perceptions of people living with disability. *Sociology of Health & Illness,* 45(6), 1223–1241. https://doi.org/10.1111/1467-9566.13559

Boardman, F. (2020) Human genome editing and the identity politics of genetic disability. *Journal of Community Genetics* 11:125–127 https://doi.org/10.1007/s12687-019-00437-4

Boardman, F. (2020) Letter to the editor. Gene editing and disabled people: a response to Iñigo de Miguel Beriain *Journal of Community Genetics* 11:245–247 https://doi.org/10.1007/s12687-020-00465-5

Boardman, Felicity Kate (2014) 'The expressivist objection to prenatal testing: The experiences of families living with genetic disease', *Social Science & Medicine*, Vol. 107, pp. 18-25. https://doi.org/10.1016/j.socscimed.2014.02.025.

Bonner, M. (2023). *Disability: Definitions, value and identity*. CRC Press.

Buchanan A. Choosing Who Will Be Disabled: Genetic Intervention and the Morality of Inclusion. *Social Philosophy and Policy*. 1996;13(2):18-46. doi:10.1017/S0265052500003447

de Miguel Beriain, I (2020) Gene editing and disabled people: a response to Felicity Boardman. *Journal of Community Genetics* 11:241–243.https://doi.org/10.1007/s12687-020-00460-w

Estreich, G. (2019). *Fables and futures: Biotechnology, disability, and the stories we tell ourselves*. MIT Press.

Feeney, O., & Rakić, V. (2021) Genome editing and 'disenhancement': Considerations on issues of non-identity and genetic pluralism. *Humanit Soc Sci Commun* 8, 116. https://doi.org/10.1057/s41599-021-00795-w

Feeney, O (2019) Editing the gene-editing debate: re-assessing the normative discussions on emerging genetic technologies′, NanoEthics: Studies of New and Emerging Technologies 13(3), 233-243 (December): https://doi.org/10.1007/s11569-019-00352-5

Garland-Thomson, Rosemarie (2019) 'Welcoming the Unexpected' in Parens & Johnston eds. Human Flourishing in an Age of Gene Editing. Oxford University Press.

Hoffman-Andrews, L., Mazzoni, R., Pacione, M., Garland-Thomson, R., & Ormond, K. E. (2019). Attitudes of people with inherited retinal conditions toward gene editing technology. *Molecular Genetics & Genomic Medicine*, *7*(7), e00803.

Hofmann, B., (2017). 'You are inferior!' Revisiting the expressivist argument. Bioethics, 31(7), pp.505-514.

Hull, R. J. (1998). Defining disability- a Philosophical Approach. *Res Publica* 4: 199-210

Huneman, P. (2020). Biological individuals as "weak individuals" and their identity: exploring a radical hypothesis in the metaphysics of science. In *Biological identity*. Routledge, pp. 40-62

Liaw, Y. Q. (2024). An analysis of different concepts of "identity" in the heritable genome editing debate. *Medicine, Health Care and Philosophy*, 1-11.

Liaw, Y. Q., Turkmendag, I., & Hollingsworth, K. (2021). Reinterpreting "genetic identity" in the regulatory and ethical context of heritable genome editing. *New Genetics and Society*, *40*(4), 406-424.

Malek, J. (2010). Deciding against disability: Does the use of reproductive genetic technologies express disvalue for people with disabilities? Journal of Medical Ethics, 36(4), 217–221. https://doi.org/10.1136/jme.2009.034645

McMahan, J., & Savulescu, J. (2023). Reasons and Reproduction: Gene Editing and Genetic Selection. *The American Journal of Bioethics*, 1-11.

Olson, E. (1994). Is psychology relevant to personal identity?. *Australasian Journal of Philosophy*, *72*(2), 173-186.

Parens, E., & Asch, A. (2000). *Prenatal testing and disability rights*. Georgetown University Press.

Parfit, D. (1984). *Reasons and persons*. Clarendon Press.

Pradeu, T. (2011). *The limits of the self: immunology and biological identity*. Oxford University Press.

Resnik D, Vorhaus D (2006) Genetic modification and genetic determinism. Philos Ethics Humanit Med 1:9

Scully, J. L. (2019) 'Choice, chance, and acceptance' in Parens & Johnston eds. Human Flourishing in an Age of Gene Editing. Oxford University Press.

Shakespeare, T. (2006). The social model of disability. *The disability studies reader*, *2*(3), 197-204.

Shakespeare, T. (1996). Disability, identity and difference. *Exploring the divide*, 94-113.

Sparrow, R. (2022). Human germline genome editing: On the nature of our reasons to genome edit. The American Journal of Bioethics 22(9): 4–15. doi:10.1080/15265161.2021.1907480.

Wendell, S, (1989). 'Toward A Feminist Theory of Disability', *Hypatia*, 4(2): 104–124.