Postnatal human genetic enhancement – a consideration of children's right to be g...

Health & Medicine



Introduction

The year is 2053. Human genetic enhancement (HGE) is safely and prevalently practiced pre- and postnatally, and is part of health care or welfare programs typically managed under the *Ministry of Enhanced Living*. Guy London is a 3-year-old infant. Guys' parents opt to purchase for him the *Deluxe Enhancement Package for Athletic & Sociable Boys*. The package offers a series of genetic modifications that guarantee, to a certain extent, that Guy's personal traits and physical characteristics will be predominantly those of a promising outgoing, popular athlete. Does Guy have a valid right to be genetically enhanced (including the right NOT to be thus modified)? Would Guy's putative right be deemed any differently if Guy were a 12-year-old boy or a 16-year-old adolescent?

This paper is about children's rights with respect to genetic enhancement (GE). In particular, it examines whether in a future reality where pre- and postnatal HGE is safely and widely practiced, a child would have a right against her parents or guardians to be genetically enhanced by them, 1 as well as the right *not* to be genetically enhanced. The paper initiates a rights-discourse on Guy's and his peers' claims with respect to their *postnatal* HGE (PoGE), by positing and attempting to answer two principal questions. The first, a future-looking question resting on positive (presently applying) law: would it be possible to derive a child's right to PoGE from contemporary core rights? The second is a normative one: should we create or recognize a novel child's right to PoGE?

Arguably, such (putative) rights-discourse can only take place in an uncontentious manner, in the realm of PoGE, where the subjects of GE are actual, presently existing individuals, as opposed to future persons of controversial moral status, e. g., embryos or fetuses, who occupy the realm of *prenatal* GE (PGE).

The scholarly literature on HGE has been typically and predominantly focused on *prenatal* enhancement. The human enhancement debate is overwhelmingly concerned with targeted genetic modification of the embryo *in vitro*, speculating on the implications of inheritable genetic alterations for future generations, for the human species as such, for the soundness of human nature and for society at large [see, e. g., Fukuyama (2002), Habermas (2003), and Sandel (2007)], while largely disregarding *postnatal*, somatic cell (uninherited) genetic modifications *in vivo*, of existing individuals. This paper, however, is concerned with the latter; particularly, with GE – narrowly defined as *purely elective*, i. e., non-therapeutic 2 genetic modification – of children. It offers an original analysis of children's (putative) right to be genetically enhanced postnatally, introducing a fresh perspective on the position of minors with regard to their own GE, and their power to make right claims in this context.

I posit that exploring particular aspects of PoGE, such as children's rights with respect to this technology, is a timely discussion (as well as a beneficial thought experiment), in the sense that such development is anticipated. This assertion hinges on the assumption that in the relatively not-so-distant future (i. e., within a few decades) scientists and technology will be able to

surmount the current scientific hurdles that stand in the way of effective postnatal manipulation of desired characteristics through somatic cell modification.

In order for such a targeted genetic intervention to be successful in the postnatal stage, two fundamental capacities are required: (1) the ability to perfectly target and correctly identify the gene(s) responsible for the traits that are candidates for enhancement and to decipher their activity. This will be particularly challenging with respect to polygenic traits (i. e., the product of the interaction of multiple genes), or complex, multifactorial traits targeted for enhancement (e. g., intelligence, athleticism). Such traits entail variation within multiple genes, and their interaction with behavioral and environmental factors. This, combined with our current epigenetics ignorance, 3 undeniably sets further hurdles for the effective enhancement of desirable traits; and (2) the capability to efficiently modify the DNA of each and every cell specialized for a particular trait elected for enhancement. Both capacities are currently gravely lacking and would present challenging problems for "enhancement-enthusiasts" scientists.

Now, once such obstacles are overcome and the PoGE technology is proved to be safe, I can easily (even if somewhat reluctantly) imagine it becoming simply another parental rearing and shaping tool of one's children. This "tool" could be analogized to several contemporary examples of postnatal biological, or biomedical non-genetic enhancements (i. e., for non-therapeutic purposes), already applied to minors, underpinning various parental (and child) motivations for shaping and improving children.

Prominent examples are: elective cosmetic surgery and human growth hormone treatment for ameliorating appearance (thereby potentially boosting the child's self-esteem and social status), and neuroenhancement by performance-enhancing psychotropic drugs (methylphenidate, e. g., Ritalin, and dexamphetamine compounds, e. g., Adderall), for enhancing cognitive abilities of *healthy* subjects (<u>Tamir, 2015</u>, p. 43–56; <u>Tamir, 2016</u>, p. 6–10).

My assumption that the scientific obstacle will eventually be surmounted, thus paving the way to the application of PoGE, is based on two things:

(a) Several emerging indications that science is steadily moving toward postnatal human genetic modification; for instance, scientific advancements such as CRISPR-Cas9, 4 a seemingly promising artificial *genome editing* technology, allowing specific, refined, and precise engineering of the human DNA (De Chant and Nelsen, 2014; Pak, 2014; Organizing Committee for the International Summit on Gene Editing, 2015). It is also "relatively safe, technically accessible, and affordable, essentially bringing about the 'democratization of gene targeting'" (Travis, 2015; Tamir, 2016). This technique uses a Cas9 enzyme that snips through DNA, like a pair of molecular scissors, guided by a small RNA molecule to a specific sequence of DNA to make the cut in a controlled way. It exploits the cell's DNA repair mechanism in humans, animals, and plants, to direct the spread of specific traits throughout a population, primarily in order to eradicate diseases and turn back evolutionary clocks (Brice, 2013; Esvelt et al., 2014). In fact, as recently as February 2016, scientists in the UK were granted permission by

the Human Fertilization and Embryology Authority (HFEA) to genetically modify human embryos in the first 7 days after fertilization, using the CRISPR-Cas9 technology for the first time in history, for research purposes of investigating miscarriages in women (<u>Callaway, 2016</u>). Now, although this genome editing technology seems to be more readily associated with therapeutic aims achieved through prenatal genetic modification, <u>5</u> there is good reason to assume that such gene-editing tool could be harnessed in the future (perhaps with some modifications) to perform predesigned PoGE, or at the very least – advance our mastery of the targeted genetic manipulation that PoGE requires. Geneticist George Church, a realistic outspoken advocate of CRISPR, indeed anticipates the inevitable spread of its use from therapy to self- and child-enhancement (<u>Perlman, 2015</u>). Potential GE-related somatic cell applications of the CRISPR technology have already been suggested [see <u>Polcz and Lewis (2016)</u>] and

(b) A reasoning based on optimistic academic attitudes accepting the eventual inevitability of GE technologies becoming part of our lives. One example for such an attitude is Nicholas Agar's " pragmatic optimism" approach (Agar, 2004 , p. 34-8), which holds that it is better to be prepared with suitable moral argumentation and well laid-out principles for what will eventually mature into existence 6 – presumably, in order to instruct an appropriate legal-social stance – than to be caught unequipped to deal with the ramifications of a novel technology. Another example is Baylis and Robert's Inevitability Thesis (Baylis and Robert, 2004 , p. 25), providing us with a more elaborated theory of acceptance of or resignation to the possibility of GE technologies integrating into our life. Their thesis generally

suggests that embracing GE technologies is an inescapable consequence of human "perfectibility and the biosocial drive to pursue perfection."

And so, in this spirit of optimism, we may reasonably assert that PoGE will emerge as an available shaping tool, making the child's putative claim right to be genetically enhanced, a relevant and legitimate subject of exploration.

Before delving into our analysis, I should make a preliminary note: since the technology of PoGE is a futuristic one and, as such, has hardly been analyzed in the academic literature, I use theoretical legal and ethical analysis of (children's) rights relying, *inter alia*, on *contemporary* legal reality, as reflected in relevant universal conventions and U. S. and UK jurisprudence. I rely on existing legal framework, with the (naïve?) expectation that it will remain pertinent to our envisaged PoGE-future, due to the obvious limitations of accurately predicting the legal landscape in a few decades' time. In short, I am fully aware of the methodological difficulties posed by the futurity of the technology and its hidden (currently unknown) implications, that make such pioneering attempts to lay the foundations for an appropriate child's rights discourse in the context of her PoGE, quite challenging.

The paper is constructed as follows: At the outset, I briefly introduce some of PoGE's distinctive features and suggest two relevant policy considerations for us to bear in mind throughout our analysis. Then, I move on to analyze the core issue of this paper – the child's rights with respect to PoGE. First, I analyze whether a child's putative right to PoGE could be a derivative right of existing core rights, by examining the theoretical suitability of several

(mostly) contemporary fundamental rights. Then, I consider the child's right *not* to be genetically enhanced by her parents/guardians, or the state, through an ethical analysis, where I critically address Joel Feinberg's notion of "the child's right to an open future," in the context of PoGE. Finally, I consider through jurisprudential analysis, whether a novel, positive, or negative child's right to PoGE should be recognized or created in the future, given the foreseeable implications of such recognition.

PoGE'S Most Distinctive Features

Focusing on GE conducted at the postnatal phase rather than on one conducted prenatally, holds certain advantages, particularly with respect to rights-discourse, which are predominantly attributed to the fact that this phase presents us with existing actual persons (children) subject for enhancement, rather than *potential*, *possible* or *future* 7 ones as in the prenatal phase. Unlike pre-natality, post-natality provides us with persons of indisputable moral status; subject of rights (and duties); individuals with a voice to assent/consent to/reject the enhancement procedure, to make claims (e. g., the right to be genetically enhanced) and express volitions (e. g., not to be genetically enhanced), and opinions (with regard to the specific traits chosen for GE by the child's enhancers) - what I have elsewhere termed "the presence benefit" (Tamir, 2016, p. 11). And perhaps, most importantly – post-natality provides us with an identity, which can both guide the enhancement plan and constrict it. That is to say, PoGE allows the enhancer to accommodate the enhancement plan (i. e., the traits targeted for enhancement) to the existing child's apparent identity (an option denied from the *prenatal* genetic enhancer).

Genetically enhancing an existing individual also entails other, more circumstantial unique features. One such feature is the "transparent environment." Namely, owing to the fact that PoGE is performed *in vivo* rather than *in vitro*, "the personal, social, environmental, and political state of affairs at the time the enhancement is carried out, is transparent to us" (

Tamir, 2016, p. 11). This confers a further advantage upon both the child candidate for enhancement and the enhancers, which I term "enhancement in context," an advantage that PGE obviously lacks.

Lastly, genetically enhancing existing individuals provides us with a relatively "flexible timeframe," for conducting the enhancement. In other words, " since we are in no rush to bring a particular (potential) individual into existence... [t]he enhancement plan could... be orchestrated to fit the enhanced child's developmental stages, in order for it to be optimally assimilated into her personality and life in general" (Tamir, 2016, p. 12). Indeed, from a present-day *scientific* perspective, it is possible that there will be a "time window" for the modification of some traits candidate for PoGE in terms of the optimal potential for enhancement, making PoGE time-sensitive, to a certain extent [see Polcz and Lewis (2016), p. 10]. Such recognition of the relative significance of the timing of enhancement in a child's life could potentially constrain the rather flexible timeframe that features PoGE. However, for the sake of argument (and with the possibility that future scientific developments will render such time windows meaningless), I shall assume that said "time windows" will not stand in the way of PoGE as such, but will at most, affect its optimality. Namely, that genetically enhancing

selective cognitive skills of 12-year-old guy, will be approximately 8 as effective as the cognitive GE of 3-year-old guy.

From an *identity-centered* ethical perspective, generally speaking, it would seem plausible that the earlier the genetic intervention takes place, the better it is for the child candidate for enhancement, in terms of the enhancement's integration into her identity and the consequent reduced risk of self-alienation, sentiments of inauthenticity and "damage" to her personal identity and self-perception (all feared-results by GE opponents; e. g., Habermas.2003). On the other hand, from an *autonomy-centered* perspective – PoGE of older children, who possess a more cohesive self-perception, better capacity for autonomy, and are better articulated in voicing their opinion with respect to the (parent- or self-motivated) GE, may be preferable. This perspective will be elaborated further below.

In sum, these features of PoGE not only allow for a proper child rights discourse to take place but will also compel us, as enhancers, to consider the position of the minor on the matter; namely, to be attentive to her preferences, commensurate with her age, and to be mindful to the putative effects of PoGE on her self-perception and narrative identity, particularly, in terms of the identity's "intrusion tolerance" for changes brought on by the act of enhancement.

And so, due to obvious shortcomings of the *prenatal* GE setting (such as non-existence and lack of standing of the subjects of enhancement), considering here the right to PoGE of *existing* children will provide forthright child rights talk that is unparalleled in the prenatal account.

The Right to Genetic Enhancement – Two Policy Considerations

The right to GE essentially means the right to be improved in a targeted manner, *via* the application of a particular technology. However, as PoGE is presently in its theoretical stage, we have no specific child's right to GE nor a pertinent rights-and-duties discourse, to rely on. The existent set of children's rights (to develop and thrive, to wellbeing, health, and well-rounded growth) – closely or *narrowly* construed – seems to refer to children's most essential needs, whereas PoGE obviously far exceeds the threshold of such "basic needs."

We therefore ought to consider whether a right to PoGE makes the case for a distinct, derivative, or a novel, children's right.

But before considering this, I should point out two general policy considerations that must be taken into account, prior to recognizing such a right:

(1) What such a right would entail in terms of desert or entitlement of the child. Arguably, one could follow here the same line of argument of those who oppose the "best interest of the child" criterion: one (even a child) cannot reasonably secure an interest to have the best of most, against the world. After all, we dare not commit parents to much less demanding child-benefiting instruments (e. g., music lessons for musically gifted children), so extending children's rights to include PoGE may seem exaggerated and overdemanding. We could also appeal to a sense of reasonableness or proportionality (i. e., human and financial resources are typically limited and

need to be allocated to several other, more pressing objectives); and to one's sense of morality, i. e., humility. But such talk is mostly intuitive.

(2) The potential clash, or conflict, between such a right and parental autonomous discretion in rearing and shaping one's children, specifically – parents' putative autonomy-derived right to genetically enhance their offspring. 9 Also relevant is the way parents' values and prioritization considerations influence their decisions and actions (e. g., parents could afford certain PoGEs for their child, yet *prefer* to otherwise influence her personality). Furthermore, recognizing a child's right to PoGE may coerce parents into shaping children in a manner which is inconsistent with their worldview or personal philosophy.

Having these considerations in mind, let us now attempt to identify potential sources for the child's right to PoGE and theorize about its nature.

Can a Child's Right to PoGE be a Derivative Right? in Search of a Suitable Core Right

The CRC (Convention on the Rights of the Child, 1989) seems like the natural place to begin such a quest even though there is no direct support for, or any indication of, " a child's right to be shaped and enhanced in a targeted manner," in the language of the convention. Arguably, it may be inferred from a core principle of the CRC – devotion to the best interests of the child, or from the spirit of the convention at large, but this would seem all too general and somewhat overreaching, for grounding a child's specific derivative right to PoGE.

Children's rights roughly consist of two main categories – both recognized in the CRC, acknowledging the vulnerability and incapacity of children and their need for safeguarding of their interests: (a) *human and civil rights*, equating children's entitlements to those of adults, e. g., the rights to dignity, autonomy, privacy, etc.; and (b) *protective rights*, such as the rights to nourishment, health care, education, etc.

On its face, a claim right to PoGE cannot be appropriately derived from core protective rights, due to the elective, non-essential, "privileged" nature of enhancement, making children's adult-like human and civil rights, a more plausible source for core rights. 10 Such perception of HGE, however, reflects our *present-day* reality, and it may therefore be inappropriate to rely on in our reference to the future, say, *circa* 2053 (the year of our opening illustrative example). We may therefore assume, that in a time where HGE is safely and widely practiced – PoGE may eventually become the norm, a near-standard tool for rearing and shaping one's child (as well as for self-improvement). This may set the threshold for basic needs somewhat higher than it is presently set. Elsewhere, I have even referred to the possibility of future society deeming certain types of GE a standard *sine qua non* necessity (notwithstanding its non-therapeutic, elective characterization), and hence the objects of children's rights (Tamir, 2016).

Against this background assumption, we can suggest two CRC-based potential candidate core rights: the child's fundamental *rights to participate fully in social and political life*, residing within the adult-like human and civil rights category; and the child's fundamental *rights to develop to the fullest*,

residing within the category of children's protective rights. We shall now consider these candidates:

The child's fundamental rights to participate fully in social life and political life (" participatory rights"). Participatory rights are about giving " an active voice" to children (UNICEF 11), i. e., a say in matters affecting their social, economic, religious, cultural, and political life; entitling them, inter alia, to freedom of thought; to the right to express opinions and be heard, and to have access to information; to the right to privacy; etc. (CRC, art. 12–17). Now, assumingly, the spreading of PoGE throughout society may set higher thresholds for participation in social and political life. In other words, given our envisaged "PoGE-inclined social climate," becoming genetically enhanced could be an implied condition for participation in social and political life in various respects, in the interest of fairness and equal opportunities. This would make participatory rights, broadly construed, potential core rights for the child's right to PoGE to be derived from. Let us now move on to consider the other CRC-based candidate core right.

The child's fundamental rights to develop to the fullest (" development rights"). Development rights are essentially about the child's right to evolve and flourish, to develop her personality, and cultivate her talents and abilities to their fullest potential. The fundamental right of children to development is generally stated in art. 6 of the CRC (along with the rights to life and to survival). Development rights in more specific contexts are protected under the CRC (art. 6, 18, 23, 27, 29, and 32) with respect to various domains: physical, mental, moral, social, personality, talent, cultural,

and spiritual (Peleg, 2013 , p. 523). (Since our business here is with domains, which directly correspond with PoGE, the latter two domains are irrelevant to our discussion.) Looking through the lenses of our "future-glasses," children's development could be broadly construed to include personal development through PoGE. Take, for instance, these present references to children's development rights under specific articles of the CRC: (a) parental responsibility "for the upbringing and development of the child" (CRC, art. 18). This may very well include parental responsibility for the child's GE in various domains; (b) directing the education of the child to "[t]he development of the child's personality, talents, and mental and physical abilities to their fullest potential" (CRC, art. 29). This may entail the provision of a cognitive and physical enhancement package, such as the kind sought for guy by his parents, in our illustrative example (the *Deluxe Enhancement Package for Athletic & Sociable Boys*).

Accordingly, the child's right to be genetically enhanced postnatally may indeed be *an instance*, a derivative, of the child's development and participatory rights, broadly construed. Or, rather, the derivative of children's development and participatory rights would be the presently hypothetical and somewhat over-demanding child's " right to be improved by the most up-to-date technologies," making PoGE – a part of a new specific class of improving technologies – a *private case* of such an instance (rather than a derivative right in and of itself). Alternatively, the child's right to PoGE could be considered as an *extension* of the right to be improved by the most up-to-date technologies, though with no independent standing (unlike derivative rights).

Another potential candidate core right for the child's right to PoGE to be derived from, is the universal "right to enjoy the benefits of scientific progress and its applications," embedded in article 15(1)(b) of the International Covenant on Economic, Social, and Cultural Rights (Gran et al., 2013). However, while HGE will definitely qualify as "benefiting, applicable, and scientific progress," deriving the child's specific right to PoGE from this general universal right, seems to be inadequate. This is due to the fact, that it is essentially a form of distributive justice claim vis-à-vis novel goods, relating to their just and fair allocation in a given society. In other words, while the essence of the right to enjoy the benefits of scientific progress and its applications is letting everyone equally to enjoy the fruits of scientific progress, the child's right to PoGE concerns a benefiting privilege for the single child, from an individual, non-social justice perspective.

Finally, I submit a more suitable, seemingly natural candidate for core human right: the "right to personal autonomy" in the sense of *self-determination*. I suggest establishing the *mature* child's putative right to PoGE on an account of minority-constrained (that is, not full-fledged) autonomy, which I shall term "minorautonomy." I shall illustrate the appropriateness of minorautonomy as a core right from which the child's right to PoGE may derive, in the following sections.

Minorautonomy

The notion of "minorautonomy" is based on the assumption that at a certain stage of minority children too are qualifiedly autonomous to a certain extent. Such autonomy is typically somewhat restrained by parents' (and state's) paternalism. While minorautonomy as a key right in the child's self-shaping https://assignbuster.com/postnatal-human-genetic-enhancement-a-consideration-of-childrens-right-to-be-genetically-enhanced/

and self-determination processes is not necessarily an original concept – its application to the issue of children's PoGE, however, *is* .

Minorautonomy features a dynamic transitory autonomy, in the sense that its limitations are gradually lifted pending adolescence and removed entirely at adulthood when one becomes a fully capacitated individual. The concept of minorautonomy is consistent with the tendency of growing respect for adolescents' autonomy and human dignity. It views late adolescents (17 years and older), 12 as borderline adults and quasi-competent agents, capable of autonomous reasoning and nearly free authorship (in the sense of being the originators) of their own narrative identity (DeGrazia, 2005, p. 294), to a certain extent. Arguably, younger preteen adolescents (10-16) years) will too be inspired by this notion, which, at the very least, stands to cultivate a sense of autonomy within them. As a result of this positive spillover effect, they may benefit from an autonomy-promoting environment that allows them to voice their opinion, commensurate with their age and individual maturity; and for their opinion to be taken into account, mainly by their parents who would consider these expressions of early autonomy legitimate and a significant part of their children's developing adult autonomy.

Minorautonomy also serves a general second-order purpose of any liberal society: grooming children into mature, personally and socially responsible right-holders, by supplying them with tools that will gradually advance them from "their childlike state of dependence, vulnerability, and immaturity" toward adulthood (Archard, 2013).

Joseph Raz, lays out his conditions of personal autonomy: (1) the appropriate mental abilities to form complex intentions and "plan their execution" (i. e., "minimum rationality"); (2) an adequate range of (morally acceptable) options; and (3) independence (Raz, 1986, p. 372-8). Arguably, a late adolescent facing the option of PoGE amongst other self-shaping options may satisfy these stipulations to a significant extent.

Support for the notion of minorautonomy may be found in the General Comment to the CRC (Committee on the Rights of the Child, 2005) on the implementation of child rights in early childhood, that is, BELOW the age of EIGHT years. The comment advocates respect for the views and feelings of the young child (sec. 14), perceiving young children as active social agents and right-holders. It also invokes the "child's capacities for autonomous decision-making and comprehension of his or her best interests" (sec. 17).

What further supports the notion of minorautonomy is the charge of arbitrariness: it essentially claims that the age of majority, that is, the threshold of adulthood, typically set at 18 in most countries – is simply arbitrary. There is no marked difference between a 17-year-old on the verge of 18 and an 18-and-1-day-year-old young person; at least, not one that justifies the dramatic change in legal status (Archard, 2013). However, it is not strictly biological age, but rather the correlation of age-related cognitive maturity with capacity, which essentially " qualifies one to have rights" (Archard, "Children's Rights"). On the other hand, as life experience has taught us, there is good reason to distinguish adults from minors on grounds of their decision-making capacity.

The CRC (art. 12) has made it a universal rule that a child's voice should be heard and her opinion taken into consideration, with respect to matters affecting the child. The article essentially "insists on the 'visibility' of children in their own right" and "requires that we recognize the value of their own experience, views and concerns" (Lansdown, 2001, p. 1). Children should therefore be encouraged to actively participate in decisions concerning them rather than be mere "passive recipients of adult's decision-making" (Lansdown, 1995, p. 2). Minorautonomy allows for minors capable of voicing their opinion, to participate in decisions such as self-shaping through PoGE.

In fact, minorautonomy already plays a progressively larger part in medical decision-making, where young people are being gradually perceived as *quasi* autonomous, "possess[ing] the capacity to appreciate their medical conditions, and ... competent to judge treatment decisions from a fairly young age" (Singh and Kelleher, 2010, p. 7). We are hence called to respect their privacy in matters such as contraceptives, abortions, sexually transmitted diseases, and drug treatment.

The legal doctrine of *mature minor*, developed in *Gillick v. West Norfolk and Wisbech Area Health Authority* (1986), binding in England and Wales (and approved in Scotland, Australia, Canada, and New Zealand), is an indication of such a determination. It has established that a minor *under* the age of 16 13 can consent to contraceptive advice and treatment from a doctor, *without parental consent* or *knowledge*, providing that she can understand what is proposed despite her young age, and that other conditions of the "Fraser

guidelines" (so termed after Lord Fraser's opinion in *Gillick*), indicating a high likelihood of her continuing to have sexual intercourse, with or without contraceptive treatment and against her best interests, are met. Notably, since initially introduced, the "Gillick competency" test has been extended beyond the realm of contraceptive advice for girls to adolescents' other welfare and medical decisions (Cornock, 2007; Blyth and Frith, 2009, p. 186).

The statutory or common-law mature minor doctrine is an exception to the rule requiring parental consent to minors' medical treatment. The doctrine is not recognized by all states in the U. S. Where it is recognized, it usually applies to 16-year or older (unemancipated) minors facing medical decisions, sometimes without parental knowledge and typically without parental consent. They are required to prove sufficient maturity and understanding with respect to the nature of the specific medical process and its consequences. 14, 15 Minorautonomy presumes that late adolescents have the required capacity and therefore the power to *consent* to PoGE (rather than merely assent in addition to parental/guardian consent).

Since we refer to personal autonomy in the sense of *self-determination*, and as we have postulated that minorautonomy can only be attributed to late adolescents on the verge of adulthood, who typically exert more than minimal self-governance, it would seem relatively safe to entrust minorautonomous young persons with such self-shaping decisions.

Nevertheless, the fact remains that minorautonomy is a *relative* right <u>16</u> and power constrained by parental autonomy and authority. And so, determining https://assignbuster.com/postnatal-human-genetic-enhancement-a-

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whether a particular minor in a particular setting is qualified to make certain (minor)autonomous decisions, will require a subjective factual determination, on a case-by-case basis.

Minorautonomy is also *issue-relative* in the sense that it is dependent on the particular kind of choice or activity in question and varies accordingly.

Namely, minorautonomy would generally apply to decisions regarding matters that are: (a) personality-defining; (b) closely linked to the minor's identity; and (c) if deferred until adulthood, such decisions might lose some of their relevance and force. 17

Consequently, where more general matters relating to participation in social life are concerned, minorautonomy will typically not apply and full-fledged autonomy will be required, even where the minor is situated on the threshold of majority: for example, a 17-year-old young person wishing to enlist in the U. S. military is required to produce parental consent (essentially rescinding minorautonomy). S/he could enlist without parental consent, as well as vote, at the age of 18, whereas in most U. S. jurisdictions, a young person will not be considered autonomous or legally permitted to consume alcohol before the age of 21.

Scientific Evidence Relating to Adolescent Decision-Making or Maturity of Judgment

The traditional empirical perception is that children and young persons have not yet acquired the decision-making capacity possessed by adults, in terms of cognitive faculties regulating inhibition, risk-assessment, problem solving, etc., and consequently engage in risk-taking behavior and impulsive conduct, making suboptimal decisions that lead to increased incidence of https://assignbuster.com/postnatal-human-genetic-enhancement-aconsideration-of-childrens-right-to-be-genetically-enhanced/

harm (<u>Cherry, 2010</u>, p. 562). This is based on a significant body of neurobiological evidence indicating the ongoing development of the prefrontal cortex, through adolescence and into early adulthood.

Casey and Caudle (2013, p. 83), claim that these are misleading overgeneralizations and that where emotional information can be isolated and the atmosphere is "cool," adolescents are "capable of acting rationally and making optimal decisions" as well as demonstrate impulse-control. In fact, under such conditions, many adolescents perform not only well, but better than adults! Similarly, the common charges against adolescents' flawed risk-assessments are rejected by Reyna and Farley (2006, p. 34), who claim that adolescents do *not* perceive themselves as invulnerable and, in fact, tend to *overestimate* risks such as HIV and lung cancer.

Steinberg et al. (2009, p. 592), suggest that 16-year-old adolescents' decision-making or maturity of judgment does not fall short of that of adults, where emotional information can be isolated; social influences are "minimized or can be mitigated"; consultants "who can provide objective information about the costs and benefits of alternative courses of action" are accessible; and a "deliberative, reasoned decision-making" process – allowed.

It would be highly speculative and difficult to envisage the typical conditions under which adolescents would make decisions regarding their own GE.

Parents and professional consultants (such as physicians, geneticists, and psychotherapists) will probably be available for guidance. Social (peer-) pressure and pressing trends, however, will be difficult to escape. In fact,

these will probably not only influence the adolescent's decision-making, but inspire and motivate it in the first place.

Notwithstanding this, the evidence (succinctly described here) cautiously suggests that late adolescents should, in principle, be entitled to make decisions concerning their self-shaping through GE.

To conclude this section, given that autonomy is a foundational right, the above analysis may indicate that the child's putative right to PoGE could, prima facie, derive from the core right to personal (minor)autonomy or, at least, that minorautonomy may create a supportive climate for the recognition of such a novel right. Purportedly, the same may be true for deriving said right from, or perceiving it as an instance of children's development and participatory rights. In fact, should we acknowledge a child's positive right to PoGE, such core rights may be more applicable to infants and younger children who cannot yet reside under minorautonomy and are merely lightly influenced by the purported (minor)autonomy-promoting environment.

A Child's Right Not to be Genetically Enhanced?

Minorautonomy equally entails the right NOT to be genetically enhanced postnatally, to be free from coerced GE. That is, since PoGE may also close some options rather than open them, the child – commensurate with her maturity – may opt *against* GE, rather than become a slave to her extraordinary capacity in a specific field through such technology.

GE proponents support such a right, on libertarian grounds. GE opponents also typically invoke such a right, while employing a different rhetoric. Jürgen Habermas, for one, invokes the child's freedom in this respect Habermas (2003, p. 49). He makes the point that "[t]he parents' eugenic freedom is subject to the reservation that it must not enter into collision with the ethical freedom of their children." Such freedom allegedly entails both the right to be genetically enhanced, and its negative counterpart - the right *not* to be genetically enhanced. Such freedom is typically constrained by parental authority and autonomy, which routinely determine children's narrative identity to a great extent and chart the path along which they make their early (often defining) steps in life. It is also constrained by the child's limited capabilities for making such resolutions and lack of the financial means necessary for carrying out the enhancement plan. So, speaking of a child's freedom to design herself (including by rejection of the option of PoGE) in absolute terms is somewhat incoherent as well as impractical. For the dominant paternalistic conception is such, that the child is a rather passive recipient of parental dictates with respect to rearing her and shaping her personality. Accordingly, children do not have a right *not* to be educated nor do they have a right *not* to be raised according to a certain religious faith at least not absolute rights. 18 By the same token, children would not have a right *not* to be genetically enhanced by their parents or guardians (or the state, where applicable). At least, not an absolute one.

<u>Fenton (2006</u>, p. 35, 39), who criticizes Habermas's negative approach to liberal eugenics, <u>19</u> powerfully makes the argument that

... the parent-child relationship is inherently one of inequality; even without explicitly choosing a child's characteristics or traits, a parent has considerable control over the development of that child and the range of options open to her for future development (emphasis added – Sivan Tamir).

However, the child's right *not* to be genetically enhanced (i. e., to be free from coerced GE 20) could seemingly be recognized as a relative right, balanced against parental autonomy in rearing one's child, which is itself constrained, in turn, by two principles: (1) the above-considered principle of (minor) autonomy; and (2) the principle of the child's human dignity. Notably, the principle of human dignity similarly applies to the child's right to be genetically enhanced but seems to apply more strongly to its negative counterpart (the child's right *not* to be thus enhanced). A nuanced outlook would suggest that the principle will typically be invoked with respect to the child's right to be genetically enhanced, in the contexts of agency and the ability to exercise free will in seeking the GE procedure. However, with respect to the child's right *not* to be genetically enhanced, human dignity will be invoked in the context of respect for the child's will (not to be genetically modified) with regard to the features of the specific enhancement project. Namely, PoGE performed *against* the child's will, the (reasonably foreseeable) outcome of which is socially adverse or personally degrading, or any PoGE that fails to respect the child's present identity-description, is deemed to harm the child's human dignity and is consequently impermissible.

Now, Habermas (2003, p. 22), also speaks of the "right to an unmanipulated genetic heritage," immune from artificial intervention. The Recommendations of the Council of Europe on Genetic Engineering (Parliamentary Assembly, 1982) similarly invoke the "right to inherit a genetic pattern, which has not been artificially changed." Such a purported right seems stifling or indiscriminately inhibiting any benefiting scientific progress that advances the goals of mankind. It also ascribes undue significance to human "genetic heritage" or "pattern," as if it has any relevance independently of an individual's identity or personality. What is more, it seems to naïvely assume that genetics, in itself, is an inviolable, deterministic legacy. Fenton (2006, p. 41), disputing Habermas, provocatively questions whether the "right to a genetic inheritance immune from artificial interference," heralded by enhancement opponents, could not in fact be rejected in favor of a "right to enhance one's genome." (She seems to think that it is quite possible, relying on moral common sense that may perceive human nature as "valuable, but in no way ... sacrosanct and inviolable.").

The Child's Right to an Open Future

Feinberg (1980, p. 124-6), has offered an elegant, oft-cited classification of rights. The *child's right to an open future* – the collective term for children's rights-in-trust – belongs to the subcategory of children's rights (C-rights) that appear as adult autonomy rights, but cannot be exercised by the child until her decision-making capacity and other features of maturity are more fully formed. Such rights are saved for her until adulthood since they are prone to violation before the child can effectively exercise them. Other scholars have

adopted various versions of the child's right to an open future, as a constraint on parental autonomy in shaping one's children (Dworkin, 1982, p. 205; Buchanan et al., 2000, p. 175; Ouellette, 2010). Some versions (e. g., Buchanan et al.'s) are weaker than Feinberg's at times stricter account of a right to "a maximally open future" (Buchanan et al., 2000, p. 170).

The child's right to an open future has been criticized for various reasons, *inter alia*, for being over-demanding, unrealistic, and conceptually vague (e. g., open to what extent? incomparable different possible futures; and ambiguity as to what makes one future more open than another) (<u>Arneson and Shapiro, 1996</u>, p. 365; <u>Mills, 2003</u>, p. 499; <u>Resnik and Vorhaus, 2006</u>, p. 6; <u>Archard, 2013</u>). I shall note my own reservations here (while my critique is chiefly aimed at the stronger version of the child's right to an open future, it also generally applies to its weaker accounts):

- (a) No one's future is truly "open." The future is somewhat unpredictable and inconstant. Things happen that continuously narrow and reformulate our future options. Invoked in the context of GE, the idea of an attainable "open future" assumes perfect control over the results of genetic modification. This seems erroneously deterministic, disregarding epigenetic 21 and environmental effects that assure us that genetic expression can be unpredictable, whether genes are in their natural or modified state.
- (b) Even adhering to the most stringent standard of neutrality with respect to the child's future (i. e., refraining from affecting her "unlimited" future life course, one way or another), as stricter accounts may have us do, could detrimentally affect her open future. Take, for example, the adoption of a

permissive parenting style. Such forced avoidance, would leave the child unguided, uneducated, in utter confusion with regard to the values she should uphold, and generally neglected and detached. Consequently, it has been argued that it is this non-interfering, open parenting manner that perhaps paradoxically "ends up being autonomy-diminishing" (De Ruyter and Schinkel, 2013, p. 382). The child's autonomy could be reduced by such parental neutrality, in two possible senses: first, since autonomy is, *inter alia*, about having an adequate range of options to choose from, limiting this range in childhood would arguably constrict the child's optional life plans; second, it would go against Raz's requirement that the exercise of personal autonomy must entail a capacity to understand *valuable*, morally acceptable (not neutral) options, from which a capacitated individual is required to choose. This critique obviously does not apply to much less demanding, weaker versions of the child's right to an open future.

- (c) The threat to a child's open future may also be invoked with respect to her *current* interests and *presently* realizable rights. Therefore, the claim right to an open future, if recognized, should *not exclusive* ly apply to rights-in-trust, but rather to *all* of the minor's interests that stand to be violated in a manner that might affect her "open" future, requiring the protection of parents/guardians.
- (d) The duration of relevancy of children's rights-in-trust, as <u>Feinberg (1980</u>, p. 148–150), himself points out, may in fact be shorter than it initially appears. Also, we lack a clear-cut line beyond which C-rights are replaced by adult (A-) rights. All we have are mere approximations. Feinberg concedes

that the point of full maturity or adulthood is *arbitrarily* fixed. In reality, C-rights-in-trust become adult rights much sooner (by the age of 10 or 12). Consequently, children beyond infancy are partly adults. In fact, children influence their own shaping from the very beginning: initially passively, by showing their "rudimentary character," and as they grow older – more actively. Parental shaping is guided by these displays of character and accordingly (at least ideally) strengthens "the basic tendencies of the child as manifested at that stage." I therefore wonder: if this is a true reflection of things, how can parents be expected to discern the actual timeframe within which they are responsible to protect the child's open future? Or, how can parents' decisions or actions to preserve such an open future be distinguished from those of the child's, when they supposedly act *in sync* with the child's own shaping of her future?

(e) Last, a particular reservation concerning the application of the right to an open future to the PoGE setting: the putative right to PoGE is a personal autonomy right, which the child cannot presently exercise (at least, not before becoming "minorautonomous"). Now, putting the exercise of such a right on hold for the child until s/he is an adult, in accordance with Feinberg's account, would self-defeat the entire purpose of PoGE. That is, since the rationale of PoGE is to provide the child with better life opportunities, by honing genetically enhanced traits and skills *throughout childhood*. So, it is in fact, the implementation of PoGE *now* that will open the child's tomorrow, rather than avoiding it now and deferring it until adulthood.

To conclude, significant genetic modification plausibly stands to constrain a child's ideally unfettered horizon, just as education, religious indoctrination, and financial limitations do. However, the child's entitlement to an "open" future is an idealistic notion, a worthy guide to some extent, but largely impracticable for the reasons cited above.

After this rather comprehensive pursuit after a derivative child's right to PoGE (emanating mostly from existing core rights), we shall now turn to examine whether a child's *de novo* right to PoGE is warranted.

Should We Create or Recognize a Novel Child's Right to PoGE?

Rights talk seems to have become overly extensive and right claims too easily made nowadays, invoking concern that "the prodigality of rights attributions is damaging to the cause of rights." L. W. Sumner and others critically observe the proliferation of rights with dwindling value and argumentative power Sumner (1987). Sumner (1987, p. 15), rather graphically describes the erosion process that a right goes through, starting out as a "specialized instrument" and gradually (due to political pressures and through the distortion/abuse of the language of rights) becoming a general-purpose one. Consequently, as a right is stretched farther and farther "beyond its proper domain," it is progressively emptied of its distinctive content, thus bringing about "increasing versatility of rights... purchased at the cost of their increasing vacuity." This seemingly calls for a policy of calculated, sparing recognition of novel rights *ex nihilo*, 22 to avoid such diminishing effects (Epstein, 1992).

Now, although there is talk about "new claims of rights being proliferated daily" (Knowles, 2001, p. 165-6), the reality seems to be that unlike the frequent appearance of such claims, which follow the emergence of new social goods reflecting certain values (such as access to the unprecedented instrument of PoGE), it is not often that new *independent* rights, entrenching such values, are legally recognized. Rather, typically, new values initially tend to be expressed through the lax interpretation or artificial extension of "old" existing rights. (It is only later, and not always, that society matures into explicit, independent acknowledgment of new legal rights.)

The legal acknowledgment of new *positive* rights is a rare occasion. (A rather fresh example is the "right to be forgotten" "in the context of digital memory and/or data retention," i. e., a right against others to have one's personal data actively erased from digital records; 23 Weber, 2011, p. 120.) Such rarity is primarily (but not exclusively) due to the nature of the democratic process, i. e., the many compromises and trade-offs in the legislative body, and the pressure exerted by various stakeholders.

Moreover, from a public policy perspective, rights (particularly *new* rights) bear significant costs and burdens when they generate new duties, in terms of informing the general public about these duties, and constructing, financing and regulating new mechanisms for realizing such rights, particularly their enforcement.

In principle, the recognition or creation of a novel positive right of the child to PoGE would also require justification. On a general level, it ought to be taken into account that the recognition of such a right will broaden the scope of presently recognized children's rights, potentially breaching it by (undesirably?) introducing a new category of children's rights (in addition to the already existing ones of the CRC – "human and civil rights," and "protective rights") – that of "improvement rights." On the other hand, seemingly, such a right would promote the interests of individuals in self-determination, self-creation, and self-improvement. Nevertheless, while children deserve to have their basic needs provided for, to thrive and prosper and to have good opportunities in life – it is not clear that they necessarily deserve the *best* or *optimal* opportunities, potentially facilitated by PoGE!

And indeed, <u>Bostrom and Sandberg (2009</u>, p. 333), maintain with respect to cognitive enhancement, that it is not quite clear "whether access to all enhancements should or would be regarded as a positive right"; whereas "[t]he case for at least *a negative right* to cognitive enhancement, based on cognitive liberty, privacy interests, and... capacity for autonomy, *seems very strong*" (emphases added – Sivan Tamir).

I agree that the case for a *negative* right would, in theory, be more plausible than that for a positive one, for the following cumulative reasons, which correlate with the policy considerations mentioned at the outset of this paper: (a) GE will most probably be available on the free market and will not be cost-free (except, perhaps, for a state-funded once-in-a-lifetime basic enhancement package); (b) a *positive right* – either derivative or a newly emerging independent one – will potentially invoke considerably burdening correlative legal (and moral) duties imposed upon parents and the state to

supply the demand for this benefiting technology; and (b1) arguably, such duties would, respectively, exceed parental obligations to satisfy the *best interests* of the child, reasonably and proportionally construed – namely, recognizing the limitations of available options, the needs, rights, and interests of others (parents and other siblings), and the fact that family members' lives are intertwined (Kopelman, 1997); as well as state's typically limited resources, additionally bound by principles of distributive justice, which may weigh against such elective expenditure.

So, while the child's interest in being genetically enhanced postnatally may be construed as intrinsically valuable to her (i. e., of *ultimate value*), <u>24</u> this is not necessarily sufficient to justify holding others (such as parents and the state) legally duty-bound on this ground (<u>Raz, 1986</u>, p. 189). Consequently, it would be hard to justify a new positive right (be it independent or derivative) based on the child's interests of self-determination and self-improvement.

However, the case for such a *negative* child's right is not compelling either, since particularly young children would typically not be the initiators of such use of shaping technology, and would actually require the active involvement of their parents/guardians in executing and financing the enhancement plan. A non-interfering, stand-off position of the latter, namely, parental/guardian neutrality in this respect, might therefore even *deny* them the promotion of their interests through GE.

Last, another policy consideration, which might bear influence on the strength of the claim for such a child's right, is what we may term the "https://assignbuster.com/postnatal-human-genetic-enhancement-a-

consideration-of-childrens-right-to-be-genetically-enhanced/

realizability factor." Whether a child's claim for PoGE is a positive or a negative right, we might have to take into account the prospects of actually realizing it. To put it more straightforwardly, in light of potential epigenetic influences, the genetic modification may be incapable of guaranteeing the fulfilment of the enhancement plan (in part or in full), exactly as originally intended. 25 Policymakers considering the acknowledgment of a child's right to PoGE, under any framework, ought therefore also to take into account that rights are too serious a matter to be protecting shaky unrealizable interests.

Conclusion

The purpose of this paper was to identify potential sources for- and analyze the nature of a purported child's right to be genetically enhanced postnatally. Due to our epistemic inability to accurately predict the future state of affairs, our analysis has relied on existing law and *presently* prevalent (Western-)liberal morality. I have examined the suitability of several potential fundamental rights to serve as core rights from which the child's right to PoGE may derive. My initial conclusions were that such putative right could, prima facie, be a derivative of the right to personal (minor)autonomy, as well as a derivative of children's development and participatory rights, in the case of infants and younger children who cannot yet reside under minorautonomy. Further exploration, however, has shown that the direct translation of any of the child's interests in GE into any kind of recognized positive or negative right - whether derivative or a newly emerging independent right - is unlikely. Such improbability is mainly attributed to the considerably burdening correlative legal (and moral) duties that a positive right to supply the demand for this non-essential technology

would impose upon parents and the state; and to the anticipated situation that likely would require the active involvement of parents/guardians in executing and financing the GE plan, which does not conform with a negative right of non-interference.

As per the putative child's right *not* to be genetically enhanced postnatally, I determined that such a right could be recognized as a relative right, balanced against parental autonomy in rearing and shaping one's child.

I believe that conducting such deliberation ahead of time is a worthy thought experiment that would be valuable for forthcoming regulatory debates, by laying down the foundations for an appropriate ethico-legal framework, before GE technologies become state-of-the-art techniques.

Naturally, any such analysis that does not grapple with the chief implication of rights – their respective duties – is incomplete. Albeit making some assumptions regarding the burden of such potential duties and its negative effect on the prospect of recognizing such a right, there are still several aspects that require contemplation: first and foremost – whether or not traditional childrearing duties, broadly construed, should encompass a legal duty to genetically enhance one's offspring, postnatally. This weighty issue deserves separate consideration.

Author Note

A concise version of this paper was presented in the "Enhancing Understanding of Enhancement" international conference in Belgrade (Oct. 2015).

Author Contributions

The author confirms being the sole contributor of this work and approved it for publication.

Conflict of Interest Statement

The author declares that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Acknowledgments

This paper is based on the author's doctoral research carried out in the Law Faculty at the Hebrew University of Jerusalem, under the supervision of David Heyd and Alon Harel. The author is deeply grateful to them both for their extraordinary guidance and invaluable advice. The author would also like to thank the anonymous reviewers for their helpful suggestions and comments.

Footnotes

- 1. $^{\circ}$ I have elsewhere also analyzed the putative duty of the state to genetically enhance children, *in lieu* of their parents; see Tamir (2015, p. 241–269) and Tamir (2016).
- 2. ^ I intentionally avoid discussing the child's putative right to therapeutic GE (i. e., gene therapy) in this paper, focusing merely on the seemingly "harder" case of *purely elective*, *voluntary* (social pressure aside) GE.
- 3. ^ Epigenetics is the inheritable external influence of lifestyle and environmental factors that does not involve changes to the DNA

- sequence, through chemical alterations to the epigenome that regulate the activity (expression) of all the genes within the genome (Jablonka and Lamb, 2006; Rothstein et al., 2009).
- 4. ^ CRISPR Clustered Regularly Interspaced Short Palindromic Repeat.
- 5. ^ See, recent report on the genetic modification of defective human embryos by Chinese scientists, employing the CRISPR-Cas9 gene editing technique (Cyranoski and Reardon, 2015). Various other therapeutic aims of this technology (e. g., treating HIV and cancer) are also presently being researched (Saayman et al., 2015 ; Liverpool, 2016).
- 6. ^ In fact, Agar has speculated, back in his well-known paper *Liberal Eugenics* (1998, p. 139), that "twenty-fifth century genetic engineers may be able to directly intervene in the genomes of existing individuals, splicing in genes for desired traits and snipping out those not similarly favoured."
- 7. <u>^ Heyd (1992</u>, p. 97), defines " *potential* persons" as " people whose existence is dependent on human choice," and " *possible* persons," as " persons who have not yet, and may not ever, come into existence." " Future persons" are " persons who do not yet but will exist," who may be included under the category of actual persons (Roberts and Wasserman, 2009, p. xiii).
- 8. ^ See *infra* discussion in footnote 17, about the life-stage-dependent realization of the *potential* for enhancement.
- 9. ^ For a comprehensive analysis of parental autonomy and rights in the context of PoGE, see Tamir (2015) , p. 137–165.

- 10. Although, according to Julian Savulescu, "...enhancement is no luxury. In so far as it promotes well-being, it is the very essence of what is necessary for a good human life Savulescu (2005 p. 38)."
- 11. ^ UNICEF (accessed July 30, 2016). *The Convention on the Rights of the Child Participation Rights: Having an Active Voice* .

 Available at: http://www.unicef.org/crc/files/Participation.pdf .
- 12. <u>^ Steinberg and Cauffman (1996)</u> maintain that "[c]ontrasts between adolescents and adults that do not distinguish between older and younger teenagers... are likely flawed." They therefore suggest creating subcategories of adolescents distinguishing between 16 and younger (early and middle adolescents), and 17 and older (late adolescents).
- 13. ^ See the UK's Family Law Reform Act (1969), allowing for minors between 16 and 18 to consent to medical treatment (it even goes as far as to regard any such non-consensual treatment as a trespass upon her person), making parental or guardian consent (where a minor's effective consent was given) redundant.
- 14. ^ "Mature-minor doctrine law & legal definition." USLegal .Available at: http://definitions. uslegal. com/m/mature-minor-doctrine .
- 15. ^ See the West Virginia Supreme Court ruling in Belcher v.

 Charleston Area Medical Center (1992) , where the court has specified the facts to be determined in establishing a mature minor status.
- 16. ^ A relative right is a right, which is not absolute (see *infra* footnote 18), in the sense that it is balanced against other fundamental rights.

- ^ This last criterion (c) hinges on the assumption that, for the 17. most part, genetically enhancing a particular trait or several traits merely gives the genetically modified individual a *potential* for enhancement. Presumably, however, in order to realize this potential, one would have to: (a) truly desire and aim to achieve a particular goal through such enhancement and (b) to be provided with the opportunity to perfect her genetic-modification-given skills, and to effectively master them to reach the desired goal. So, it is the loss of opportunity, specifically in terms of its timing, that raises concern in this respect. For example: if a highly motivated, competitive minor wishes to enhance her athletic abilities in order to become, through supplemental training, an outstanding athlete - putting such enhancement on hold until she becomes legally mature, say, at the age of 18, will hardly be relevant or effective, as she would have " squandered" away years potentially dedicated to honing her genetically-enhanced athletic skills.
- 18. Absolute rights are such rights that are intrinsic to human beings, as such; ones that it is the duty of everyone to respect. And in the words of Gewirth (1981, p. 2): "A right is absolute when it cannot be overridden in any circumstances, so that it can never be justifiably infringed and it must be fulfilled without any exceptions."
- 19. ^ "Liberal eugenics," is the idea of parental freedom in choosing the genetic characteristics or design of their children, and state neutrality in this respect. See Agar (1998, 2004).

- 20. ^ Plausibly, *everybody* (not just children) will have a right to freedom from coerced genetic manipulation.
- 21. ^ For a comprehensive account of epigenetics and genetic determinism in the context of PoGE, see Tamir (2015) , p. 62–79.
- 22. ^ The term " *ex nihilo*" should be broadly construed here in the sense that the foundation for the new right was already laid by existing neighbouring rights but the new right, *per se*, is unprecedented.
- 23. ^ The " right to be forgotten" " reflects the claim of an individual to have certain data deleted so that third persons can no longer trace them... [it] is based on the autonomy of an individual becoming a right holder in respect of personal information on a time scale" (Weber, 2011, p. 121). The right is recognized in EU law [" the right to erasure ('right to be forgotten')," Regulation (EU) 2016 /679, art. 17 and Directive (EU) 2016 /680]. Its status, however, is somewhat perplexing. While it may be considered for a status of a new fundamental right within the body of human rights, it could also be merely a derivative right of the fundamental "right of the protection of personal data," recognized in article 8(1) of the Charter of Fundamental Charter of Fundamentalghts Right of the European Union (2012). On the other hand, art. 8 does not specifically refer to the option of erasure of personal data. Also of interest with respect to the nature of this right, is the ruling of the Court of Justice of the European Union in a case brought before it (Google Spain SL v. Agencia Española de Protección de Datos, 2014), where "the Court explicitly clarified that the right to be forgotten is not absolute but will always need to be balanced

against other fundamental rights, such as the freedom of expression and of the media (para 85 of the ruling)" (European Commission, 2014). I shall not delve further into this intriguing novel right, as it exceeds the scope of this paper.

- 24. ^ Raz (1986, p. 177–180), maintains that a right should be based upon an interest of *ultimate value*, which he defines as one that is "... non-derivative..., intrinsically valuable... independently of one's instrumental value."
- 25. ^ This suggestion hinges on the assumption that the understanding and control of epigenetic mechanisms will remain limited as they *presently* are. However, it is not improbable that by the time PoGE will be prevalently practiced, the enigma of epigenetic effects will also be resolved, hence making any such reservations redundant.

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