

Sport as a human right and genetic testing for talent identification: opportunities and risks

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Abstract: In today legal framework, sport is qualified as a human right. This has implications for the understanding of what is permissible in sport practice to ameliorate sport performance and selection of athletes. Genetic talent identification is highly questionable when framed within the human rights approach to sport, including elite sport. As a matter of fact, the qualification of sport as a human right makes it part of a bundle of interconnected rights among which the right to freely construct one's personality is at center stage. How far can science go in identifying talents without violating fundamental rights? What kind of regulation should be provided in order to put scientific advances in this field on a human rights footing?

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Introduction: putting genetic advances in context

Elite sport is one field of human activities where individual top performance is an essential feature for participants. Thus, it is one field of human activities where the ideal and achievement of perfection is carried to extreme consequences. In fact, the quest for high performance often hides the search for 'super-human' performance, that is, exceeding limited human nature. This is testified by various attempts to increasingly cross the borders of physical limitations by transforming the human being into the "homo possibilis"². In the field of sport, paradigmatic examples of this trend are the Paralympics. In this context, the story of Oscar Pistorius is very telling.³ Indeed, some of the post-human reflection has focused on paralympic athletes in order to highlight that transformation of human nature is already a concrete reality.⁴

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² S. RODOTÀ, *Il diritto di avere diritti*, Laterza, Roma-Napoli, 2012, p. 349.

³ *Ibidem*.

⁴ The debate around cyborgs is often framed with reference to paralympic athletes, see S. SALARDI, *Lo sport come diritto umano nell'era del post-umano*, Giappichelli, Torino, 2019.

Recebido em 07/11/2020
Aprovado em 11/11/2020

Following a post-humanist perspective, in particular with regard to the transhumanist current,⁵ progress in science and technology will play a major role in overcoming the idea of finitude and physical limitation as the physical body is perceived as totally malleable by technology. In this scenario human (bio)enhancement becomes one key word to guide scientific and technological advances. Not only should these progresses aim at improving and widening the range of therapeutic interventions to heal diseases, but they ought to increase, ameliorate, or even create physical or cognitive abilities that humans possess or may possess in the future. (Bio)enhancement can be achieved by means of pharmaceuticals or other biomedical devices and by directly intervening on the brain and/or the body of human beings.⁶

In the debate on human (bio)enhancement different levels of discourse, various disciplinary perspectives as well as contrasting philosophical-ethical approaches can be distinguished and identified.

Despite the great interest for all the nuances of this debate, in this paper I want to focus my attention on a less known practice, this being genetic talent identification (genetic TI).

Genetics is one major driver of scientific progress today, for this reason this discipline also plays a key role in processes like medicalization of society⁷ and in expanding biomedical interventions in healthier population.⁸ This trend has led to new areas of application of genetic testing far beyond the therapeutic realm, one being identification of athletic talent. As with most biomedical innovations, this use of genetic tests has both constructive and more ethical-legal problematic implications. The aim of this paper is to highlight some underestimated impacts of

⁵ Transhumanism is a specific and well-structured philosophical current within the broader post-humanism movement. For a critical legal-philosophical approach to this philosophical current see F. H. LLANO ALONSO, *Homo Excerlsior. Los Límites ético-jurídicos del Transhumanismo*, Tirant Lo Blanch, 2018. See also J. TESTART and A. ROUSSEAU, *Au peril de l'humain*, Science Ouverte, Seuil, 2018.

⁶ See A. BUCHANAN, *Beyond Humanity. The Ethics of Biomedical Enhancement*, Oxford University Press, Oxford, 2011; At the European institutional level the first comprehensive study on the topic was released by the PANEL FOR THE FUTURE OF SCIENCE AND TECHNOLOGY (STOA), *Human Enhancement Study*, 2009 [https://www.europarl.europa.eu/stoa/en/document/IPOL-JOIN_ET\(2009\)417483](https://www.europarl.europa.eu/stoa/en/document/IPOL-JOIN_ET(2009)417483)

⁷ See P. CONRAD, *The Medicalization of Society. On transformation of Human Conditions into Treatable Disorders*, The John Hopkins University Press, Baltimore, 2007.

⁸ The expansion of genetic testing to include healthy people has been studied since 1990s when a new category was coined 'unpatients', see A. R. Jonsen, S. J. Durfy, W. Burke, A. G. Motulsky, *The Advent of the Unpatients*, in *Nature Med.*, 2:6, 1996, pp. 622-624.

genetic talent identification on the legal qualification of sport as a human right. Both in the UNESCO model as well as in the European one, sport is a fundamental right to construct one's personality, and European states are committed to safeguarding a model of sport with social, ethical, cultural, and educational functions.⁹ In discussing ethical questions arising by scientific and technological advances, the legal aspects cannot be put aside. Framing the inquiry in terms of scientific challenges and technological advances affecting the legal qualification of sport as a human right implies more general considerations about the future role of sport in our society. In other words, the legal qualification of sport as a human right demands for measuring any use of scientific and technological progress in that field against possible violations of human rights such as right to health, right to equality, right to self-determination and so on.

In what follows, a critical discussion is presented concerning the use of genetic TI in relation to the legal qualification of sport as a human right.

Genetic talent identification: origin, definition, and ethical problems

In order to correctly tackle the topic of this paper, we need to preliminary sketch the outlines of genetic talent identification and put it in context. Talent identification started in the 20th century, though the search for constitutive factors that distinguish between a champion and a simple athlete can be traced back to the ancient Greeks. Indeed, the following questions have been a long-lasting *Leitmotiv* in the history of sport activities: What makes an athlete a champion? Is genetic luck or sheer force of will and obsessive training? Is there a perfect athlete?

If it is undeniable that the fascination for perfect athletic gestures is an enduring feature of sport activities during centuries, today search for talent differs significantly from past attempts to identify the key elements of athletic talent as it is a truly scientific-based inquiry. This scientific investigation started in the first half of the 20th century as exercise physiology

⁹ See for Europe the 1992 European Sports Charter by the Council of Europe; the 1997 Declaration n. 29 on sport as part of the Amsterdam Treaty; the Helsinki Report on Sport 1999, Report from the Commission of the European Council with a view to safeguarding current sports structures and maintaining the social function of sport within the Community framework; the 2007 White Paper on Sport by the Commission of the European Communities. See for UNESCO, the 1978 International Charter of Physical Education and Sport.

became one major research topic and a matter of medical interest in Western countries.¹⁰ In Europe, the process of medicalization of elite sport started in the period of totalitarian regimes¹¹. In this period, selection of athletes has its origins. In Italy, for instance, a mandatory periodic clinical examination of physical fitness was introduced during the fascist regime. The aim of such test was to achieve: «a classification [...] of biotypological and anthropometric parameters of athletes, and consequently a selection of those individuals best suited to competitive sport, in the name and on behalf of the regime.»¹²

This kind of test is termed traditional talent identification (TI) that can be defined as «the earliest possible selection of auspicious athletes with the goal of systematically maximizing their potential.»¹³

The genetic TI is a new version of TI made possible by discoveries in the field of genetics. Genetic TI is achieved by means of genetic tests. These «determine DNA variants (polymorphisms) that are directly or indirectly associated with the disposition for sports-related skills.»¹⁴

Genetic TI depends indeed on the available technologies that permit us to ‘read the book of life’¹⁵, namely to see under the surface of our bodily structure. This molecular gaze¹⁶ makes individuals intelligible at the deepest level of their physical being and opens up for engineering and transformation of life¹⁷.

One major consequence of this molecular investigation having ethical charged outcomes was the raise of a reductionist/deterministic view on human nature: we are our genes.

¹⁰ In the USA the Harvard Fatigue Laboratory, grounded in 1926, was considered one main promoter of this discipline.

¹¹ In Italy during Fascism sports become object of medical research, see E. LANDONI, *Gli atleti del duce. La politica sportiva del fascismo 1919-1939*, Mimesis, Milano, 2016.

¹² Translation by the author of the paper. Original sentence: «classificazione quanto più rigorosa possibile dei parametri biotipologici e antropometrici degli atleti, e della selezione quindi dei soggetti più adatti all’attività agonistica, in nome e per conto del regime», cfr. E. LANDONI, *Gli Atleti del Duce. La politica sportiva del fascismo 1919-1939*, Mimesis, Milano, 2016.

¹³ S. BREITBACH, S. TUG, P. SIMON, *Conventional and Genetic Talent Identification in Sports: Will Recent Developments Trace Talent?*, *Sports Med.*, 2014, 44: 1489-1503

¹⁴ *Ibidem*, 1493.

¹⁵ L. KAY, *Who wrote the book of life? A history of the genetic code*, Stanford, Stanford University Press, 2000.

¹⁶ The metaphor of gaze was used by Michel FOUCAULT in his book *The Birth of the Clinic. An Archeology of Medical Perception*, Tavistock Publications, London, 1973, to investigate the different methodologies developed by medicine to describe the relationship between malady and bodily parts.

¹⁷ As illustrated by Nicholas ROSE in his book *The Politics of Life Itself: Biomedicine, Power, and Subjectivity in the Twenty-first Century*, Princeton University Press, New Jersey, 2007.

The problematic emotional and psychological impacts on individuals of this perspective have been long since denounced by different international organisms before genetic testing was used outside the therapeutic field.¹⁸ Despite these concerns, this conception is deeply rooted in the mind of individuals and society. As a direct consequence of this conception, over time genetic explanation has become the most popular narrative to depict and classify individuals far beyond the medical field. This is testified by the attempts to limit explanation of what makes a person a talented one from a genetic viewpoint. The reductionist narrative is so deeply ingrained in the sociocultural fabric of our societies that it seems to be the ‘natural’, read ‘good’, way of classifying people. This has implications also for genetic TI which has rapidly been understood as the only natural way of selecting athletes.

However, the search for the gene of talent is territory fraught with ethical minefields.

First of all, to focus solely on the genetic make-up means to lose sight of the complexity of elements that contribute to making a person a talented one. In other words, this genetic perspective fails to give a comprehensive overview of all the aspects involved in talent.¹⁹

Secondly, this genetic-based approach to talent assumes a shared agreement on the definition of talent, which is missing in the literature on the topic. Some authors differentiate between giftedness and talent²⁰. Others point at force of will and obsessive training as the key point in the discussion on talent.²¹ And some maintain that what makes a person a talented one is the interplay between genes and factors like environment, training and so on.

Despite the debate about what constitutes talent and what is the exact contribution of genes and training to the achievement of high-level performance in sport is far from being over²², in many cases the genetic make-up of an individual is mistakenly considered the sole key to explain what makes the difference between an athlete and a champion. This occurs, as

¹⁸ See for instance the 2002 Report by Nuffield Council on Bioethics entitled *Genetics and human behaviour. The ethical context* available at <https://www.nuffieldbioethics.org/publications/genetics-and-behaviour>.

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²⁰ See F. GAGNÉ, *Giftedness and talent: re-examining a re-examination of the definitions*. *Gift Child Q.* 1985, 29(3):103–112 and *From giftedness to talent: a developmental model and its impact on the language of the field*, in *Roeper Rev.* 1995;18(2):103–11.

²¹ J. BAKER, S. HORTON, J. ROBERTSON-WILSON, et al. Nurturing sport expertise: factors influencing the development of elite athlete, in *J Sports Sci Med.* 2003, 2(1):1–9. See also the debate around the 10'000 hours to expertise rule that was pioneered by K. Anders Ericsson, who actually called it ‘deliberate practice framework’. K. ANDERS ERICSSON, K. NANDAGOPAL, and R. W. RORING, *Toward a Science of Exceptional Achievement. Attaining superior performance through deliberate practice*, in *Ann N Y Acad Sci* 2009, 1172:199–217.

²² K. DAVIDS and J. BAKER, *Genes, Environment and Sport Performance: why the Nature-Nurture Dualism is no Longer Relevant*, in *Sports Med.* 2007, 38(11):961–980.

Susan Oyama deftly noted, because scientific explanations especially of a genetic nature tends to trump non genetic causes and reasons²³.

This dangerously seductive and equally misleading conception has in some cases contributed to replace conventional talent identification with genetic identification. As noticed, this trend is highly questionable as it assumes that the question of what talent is can be answered based solely on a strict biological view: inherited gifts depending on genetic luck prevail over training and other 'environmental factors'. And to focus solely on genetics means to neglect the real state of the art of genetic developments and to overestimate the current findings in the field.²⁴

Genetic testing for therapeutic purposes

While discussing the use of genetic testing in sports for sports performance prediction we should not forget that beside the innovative application for talent identification, these techniques are also employed for preventative purposes. This use is framed within the therapeutic purposes and arises peculiar ethical-legal questions different from those concerning talent identification. Justification for administering predictive genetic testing to early identify talented athletes is still ethically and legally questionable as the debate has not cleared up all the impacts of this use and legal solutions are still rare. Instead, ethical questions regarding predictive genetic testing for prevention have been long since discussed and solutions have been adopted at the legal level starting the 1980s, especially in the European context. I will focus here on genetic tests for preventative purposes and then detail the problems concerning genetic talent identification in the following paragraphs.

Genetic testing for prevention serves the purpose of identifying gene mutations that predict possible future outcomes in terms of health problems. These predictive tests search for gene mutations responsible for development of future diseases or disorders. However, their presence is just one part of the story. Indeed, environmental factors play a relevant role in the

²³ S. OYAMA, (2000). *Evolution's Eye: A Systems View of the Biology-Culture Divide*, Durham, Duke University Press, 2000, p. 176.

²⁴ *Ibidem*, p. 1499. As pointed out by BREITBACH et al.: «While the conventional talent research is paying attention to longitudinal test designs and multidisciplinary testing, the genetic testing is still restricted to the investigation of basic traits such as endurance or strength performance. Analytical considerations have been proposed within the field of genetic testing concerning the feasibility of gene-based studies and the low probability of existing sports talents.»

development of the gene-related disease (gene-environment interplay). Thus, the outcomes may vary a lot depending on environmental factors. In sports, genetic testing for prevention may focus on diseases with high-risk potential for the life of athletes like gene testing for (inherited) heart diseases or may be employed for identifying gene mutations for far less risky diseases like those affecting bones and tissues causing potential injuries to tendons and ligaments²⁵. In the first case, when the risk of developing a disease with fatal outcome is high, exclusion from sport career without taking into account other aspects including the individual's opinion may be justified by choosing the right to health to prevail over others, like the right to freely construct one's personality which is particularly relevant in case of minors. However, in cases in which predictive genetic tests for TI are used to identify non-life-threatening illnesses like those causing potential injuries to tendons and ligaments, justification of exclusion from sport career based on such prediction requires a deeper analysis of the reasons to support this decision. A first aspect to be taken into account is quantitative. For young individuals strongly motivated to become athletes and investing in this career since childhood exclusion from sports should be grounded in a high probability to be seriously injured and with relevant impacts for a 'future of value'. A second aspect is of an economic nature. In circumstances in which probability of repeated and constant injuries is not high the decision should be made by the athlete. This would prevent the risk that sports clubs or organizations exclude individuals based solely on economic and financial factors. As a matter of fact, a sports club or organization may be interested in not investing money on individuals who present mutations like some variants of the gene COL1A1 and COL5A1 in order to avoid insurance costs for these athletes. In these cases, the hidden message that genetic selection based on therapeutic reasons imparts is that only those with a perfect normal genome can try the sport career and that success in sport depends just on genetics. Moreover, to accept such a conclusion would validate the belief that a perfect normal genome exists and that all the rest is undesirable and should be changed.²⁶ It

²⁵ Predisposition associated with Career success (COL5A1 gene variants previously associated with reduced soft tissue injury risk are associated with elite athlete status in rugby, see S. M. HEFFERNAN, L. P. KILDUFF, A. G. WILLIAMS, et al. 2017, in *BMC Genomics*, 18 (Suppl. 8): 820, pp. 29-131.

²⁶ This conception seems to comply with the idea that «Behind every sport is a story about genetics. Not a story about the science of genetics, or even a self-conscious awareness of the genetic basis of much that distinguishes athletes [...]. But in the selection of players, in the rules of our games, and in the biases that sprinkle sports history, genetics lurks as a hidden factor», W. MILLER BROWN, *Genetics, Science Fiction and the Ethics of Athletic Enhancement*, in M. McNamee and W. J. Morgan (eds.), Routledge Handbook of the Philosophy of Sport, Routledge, London, 2015, pp. 351-367, p. 351-

reinforces the stigma of diversity²⁷ in direct contradiction to the commitment of sport to non-discrimination, including genetic discrimination.²⁸

In addition to the abovementioned problematic aspects of genetic tests for preventative purposes, following a too strict genetic approach in sport causes the ghost of reductionist and deterministic views on humans to haunt especially in elite sport. This reductionist view was a major concern of the international, European and national regulations on genetic testing for therapeutic purposes. And it was clearly prohibited. Thus, there seems to be no good argument in favor of exclusion of athletes (patients) from the legal protection provided to general patients in general. And this at least for two reasons: first, because the practice of discrimination, being direct or indirect, has the potential of creating subgroups of disadvantaged athletes especially targeting vulnerable categories like minors and women; and secondly because to rely on existing rules protecting patients may contribute to avoiding selection of athletes being solely based on economic and commercial motivations. Thus, predictive genetic testing for therapeutic and preventative purposes should be used to guide decisions in the best interest of athletes, especially young ones, namely decisions concerning the most suitable sport activities or how to tailor training regimes²⁹ given some constitutive factors and all things considered. This use seems to be the most compliant with implementation of sport activities in line with the qualification as a human right.

Sport as a human right: a(n) (ir)relevant legal qualification?

Before addressing the link between genetic TI and sport as a human right, we need to explain what we gain by framing questions in terms of human rights. To speak about sport as a human right is to say that as part of their basic human rights individuals including athletes have certain entitlements in relation to developing physical, psychological and social well-being, and

²⁷ As was the case when the story of Y chromosome genes in elite female athletes with 46, XY disorder of sexual development, was first made public M. A. FERGUSON-SMITH and L.D. BAVINGTON, *Natural Selection for Genetic Variants in Sport: The role of Y Chromosome Genes in Elite Female Athletes with 46, XY DSD*, in *Sports Med.*, vol. 44, n. 2, 2014, pp. 1629-1634.

²⁸ Genetic discrimination is defined as: «discrimination against an individual or against members of that individual's family solely because of real or perceived differences from the “normal” genome in the genetic constitution of that individual», see R. M. NATOWICZ, J.K. ALPER, J. S. ALPER, *Genetic Discrimination and the Law*, in *Am. J. Hum. Genet.*, 50, 1992, pp. 465-475, at p. 466.

²⁹ NUFFIELD COUNCIL ON BIOETHICS, *Sports Science and Medicine: Ethics*, 2014, at p. 4, available at <https://www.nuffieldbioethics.org/publications/sports-science-and-medicine>

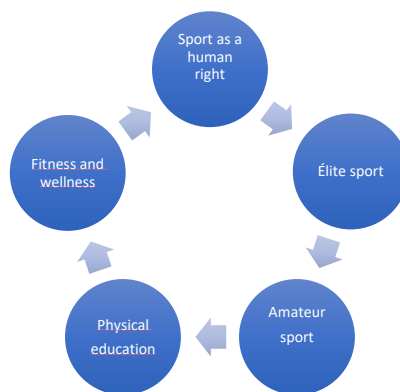
capabilities. And governments as well as educational institutions have the duty to make it possible. This is a strong statement allowing rights-holders to freely pursue their goals supported and not hindered by political institutions.

As a matter of fact, the advantage of approaching an issue through a rights framework is that it enables the realization of individual and group autonomy in the strong sense of free constructing one's personality and identity. The free construction of one's personality is a key right of post-war constitutions in Europe and an essential element of the European Charter of Fundamental Rights. This right is based on the concept of self-determination, which is, as Stefano Rodotà deftly illuminated, «identified with the life plan pursued by the person concerned [...] for it is governed by the uninterrupted exercise of sovereignty, enabling that free construction of personality which we find enshrined at the outset of our own constitution as well as in others.»³⁰ This concerns all individuals, including those who would like to try a sport career at the highest level

As regards sport, the legal qualification as a human right demands for individuals to have the possibility of freely developing their personality through the different activities that are labelled under the notion of 'sports', ranging from physical education, fitness to the highest level of sport performance (élite sport). This right to freely construct one's personality is not a monad, independent from other fundamental rights. Once sport is qualified as a human right, this qualification places it within a framework of universal, interrelated, indivisible, and interdependent rights: the right to self-determination and to freely construct one's personality are interrelated to the right to health, to the right to respect for the dignity of the person, to the right to non-discrimination and to equality and so on. All these rights have to be balanced and specified according to the characteristics of each single case. In sport issues, a first step towards specification of the abovementioned rights in order to achieve more concrete guidance is represented by those norms that are summed up under the expression *spirit of sport*. This expression refers to concrete behaviors to be implemented in order to comply with the pedagogic, cultural, ethical, and legal vision of sport: to respect for rules and laws, respect for self and other participants, fair play, ability to accept defeat, no doping and so on.

³⁰ S. RODOTÀ, *Editorial*, eds. Carla Faralli, in *Informed Consent in Medicine: Ethical and Juridical Aspects*, Salute e Società, FrancoAngeli, 2013, p. 11; on self-determination see also Patrizia BORSELLINO, *Bioetica tra 'moralì' e diritto*, 2009, Cortina

All these rules, being technical or ethical, concern elite sport as well as all levels of sport activities. They are all constitutive of sports in the human rights vision. To argue that some of these rules, in particular the ethical ones like those concerning doping, can suffer some exceptions means to put in question that legal qualification. And this may have relevant implications for sports at the different levels. Indeed, another relevant outcome of the qualification of sport as a human right is that it allows to connect all sport activities in a circular virtuous relationship between different, but interdependent, degrees of sports as shown by figure 1.³¹

Figure 1³²

The qualification of sport as a human right represents both the ultimate goal to be achieved and the principle that originates the whole pedagogic-educational process following a human rights approach.

If the different activities are interrelated, this means that what occurs at one level has relevant impacts on the others. Decisions taken in elite sport to breach rules, for instance allowing doping or selecting athletes based only on their genetic make-up, would overwhelm

³¹ This is the ideal pursued by the 1978 UNESCO International Charter of Physical Education and Sport. In article 3.3 the Charter states: «Even when it has spectacular features, competitive sport must always aim, in accordance with the Olympic ideal, to serve the purpose of educational sport, of which it represents the crowning epitome. It must in no way be influenced by profit-seeking commercial interests.»

³² Copyright from Silvia Salardi, *Lo sport come diritto umano nell'era del post-umano*, Giappichelli, Torino, 2019, p. 51.

all the other activities at a lower level. And the question is whether this would have positive effects in the long run on sports and more in general on society. I leave this question open as I do not have a conclusive response, but my impression is that the answer could be negative.

I want to conclude this paragraph with two further considerations that may help the reader grasp the relevance of the legal qualification of sport as a human right. This is indeed the extraordinary result of the political-legal vision that guided Europe after World War II. In fact, if from a scientific viewpoint it is possible to identify a continuum between the first and the second half of that century, this operation fails with regard to the political-legal scenario.

During the totalitarian regimes, as was the case in Italy, sport served to impose and export the regime's view on society. The 1928 Charter of Sport stated that the main objective of the National Olympic Committee was physical and moral enhancement of Italian *race*. This view on sport changes radically with the new political scenario. After the war, sport becomes the main promoter of equality and non-discrimination in direct contradiction with the previous mandate under the totalitarian regimes. This all occurs within the same century when the political wind turns.

How is this dual use of sport possible? How can sport be defender of equality and promoter of discrimination? In order to explain this dual use of sport in society we should recognize that a definitional constitutive feature of this activity is its *minimal social function*³³. This notion refers to the ability or capacity of sport to create, strengthen, and maintain over time social and interpersonal relationships between active participants (athletes) and passive participants (spectators). Put it simply, sport activities play a minimal role of aggregation and connection between all actors involved. This 'minimal social function' is grounded in a motivational force towards aggregation mainly based on emotions than on rationality. By means of this 'minimal social function' sport can be used to widespread different and even opposite ethical messages.

This dual use highlights an essential, albeit often disregarded, aspect of the relationship between sport and values, namely that it is not necessary, but contingent. Put it differently, values are a contingent variable promoted by means of a constant, namely the 'minimal social function'. This constitutive definitional element of sport allows to use it to support very

³³ This is the English translation of the expression I coined in Italian 'funzione sociale minima'.

different models of civil and social coexistence as well as opposite understanding of its pedagogic function.

Bearing in mind those considerations, we can try to assess some axiological inconsistencies concerning the practice of sport and its qualification as a human right. The fact that sport and values to be promoted by its means are not necessarily bound, this can explain why even in today scenario the motivational component (the minimal social function) can be exploited to surreptitiously affirm ethical contents through sport practice that *de facto* contradict those stated in formal rules.

As we will see in the following paragraph, some uses of genetic TI may may go in this direction.

Sport as a human right and genetic talent identification: what rules for what purposes?

Having discussed in the previous paragraphs some of the most relevant problems being scientific and ethical of genetic TI, in this paragraph I want to discuss whether it is possible to put this phenomenon on a formal human rights footing.

At the International level the existing *soft law*³⁴ do not directly deal with genetic testing for non-medical purposes. In any case, according to these soft law documents when genetic tests are used for medical purposes they cannot be the tool to discriminate between individuals, and in particular against workers. This general rule can be extended also to athletes. Indeed, «the use of genetic information to make determinations about selection and employment could disproportionately interfere with an individual's human right to be free from discrimination on the basis of their genetics».³⁵

At the regional level, the use of genetic TI in professional sports would not be permissible under Article 12 of the European Convention on Human Rights and Biomedicine

³⁴ The UNESCO 1997 Universal Declaration on Human Genome and Human Rights as well as the 2003 International Declaration on Human Genetic Data; the 2007 OECD guidelines for quality assurance in molecular genetic testing; the 2017 WMA Statement on Genetic Counseling and Genetic Engineering are all committed to respecting quality standards, ensuring informed consent and data protection. In particular, the UNESCO Declarations clearly prohibits discrimination based on genetic-make up.

³⁵ See S. PATEL and I. VARLEY, *Exploring the Regulation of Genetic Testing in Sport*, in *Entertainment and Sports Law Journal*, 17:5, 2019, pp. 1-13, at p. 2.

Convention (Oviedo Convention).³⁶ This Convention is the first attempt to put advances in science on a formal human rights footing. Dating back to 1997, this legally binding regulation does not take into account the use of genetic testing for non-medical purposes, thus the application of the Convention to genetic TI in sport is a matter of legal interpretation. Some authors tend to be reluctant to apply rules designed for other purposes to sports organizations, governing bodies, and employers as they argue that sport has a special essence best preserved by means of autonomous rules and a distinct discipline. However, what is neglected following this argument is that sport as a human right places it within a framework of rights which cannot be affected by any power. This framework limits the “sphere of undecidable”, as Luigi Ferrajoli terms it. In this sense, they protect individuals against any form of power, not only state power but also economic and technological one. The narrative of human rights allows to place any person in any circumstance of her life at the center of institutional attention demanding that economic and technological interests, albeit relevant in the concrete lives of people, do not become the only measure of the person’s existence.³⁷

Genetic TI in sport raises also issues of autonomy and consent, of privacy and confidentiality, and of breaching the right to freely construct one’s personality, to non-discrimination and to health. Can an athlete refuse to take a test for TI? How are information protected in terms of privacy and confidentiality? Does GDPR³⁸ and other rules apply to sports? What about athletes who are still minor? In order to adequately answer these questions what is needed is a revised normative framework for genetic testing for non-medical purposes where application to sports is clearly explained and ruled.

It is time for European institutions and national legislators to provide a regulation on genetic testing for non-medical purposes if we want to preserve individuals from abuses. The field of sport needs to be taken into account in a dedicated way and not be incorporated in provisions concerning in general talent identification through genetic testing as is the case of the Swiss new Federal Act on Human Genetic Testing.

³⁶ The Convention on Human Rights and Biomedicine by the Council of Europe states in Art. 12: «Tests which are predictive of genetic diseases or which serve either to identify the subject as a carrier of a gene responsible for a disease or to detect a genetic predisposition or susceptibility to a disease may be performed only for health purposes or for scientific research linked to health purposes, and subject to appropriate genetic counselling.»

³⁷ S. RODOTÀ, *Il diritto di avere diritti*, Laterza, Roma-Bari, 2012, p. 153.

³⁸ European General Data Protection Regulation 679/2018.

Switzerland is indeed the first country in which the existing regulation on genetic testing passed in 2004 has undergone a total revision. The new Federal Act will enter into force in 2021.

The 2004 version still in force focused on genetic testing for medical purposes. The new Act tries to fill the gaps of the previous Act like for instance the lack of an adequate regulation of genetic testing for commercial purposes. In this scenario, Chapter 3 of the new Act is dedicated to non-medical uses. After listing in Art. 31 the categories of genetic tests for non-medical purposes³⁹ which include genetic testing aiming at detecting characteristics of personality worthy of specific protection among which there are genetic testing for TI, the following Article 32 focuses on information. It underlines that in addition to all information given to a person in case of genetic testing for medical purposes as provided in Article 6, in case of genetic testing for non-medical purposes the person should receive information concerning the laboratory performing the genetic analysis even in case of foreign companies and laboratories. Information is written and includes contact data of an expert who can answer questions and of the data controller. Incidental findings cannot be communicated to the person who undergoes genetic testing (Art. 33). Only health care professionals operating in the field where the test is required can prescribe a genetic testing for non-medical purposes (Art. 34). For cytogenetic and molecular genetic testing concerning tests for non-medical purposes an authorization is needed from the Federal Office of Public Health (Art. 35).

Whereas the attempts of the revised Act to strictly link the use of non-health related tests to health care professionals in the field of genetics and to the basic requirement of a transparent information, the Act fails, in my opinion, to further limit the use of these tests based on considerations of clinical validity and strong scientific evidence. To really put the use of genetic tests for talent identification in sports as well as in other disciplines on a formal human rights footing preserving athletes from discrimination would require a harmonized regulatory framework on genetic testing both for medical and non-medical purposes based on clinical validity and appropriateness. As other existing regulations will soon need to be revised as they are no longer up to date, this would represent a good opportunity for the European Union to

³⁹ Article 31 clarifies that these genetic testing include: tests concerning physiological characteristics whose knowledge could impact on lifestyles; personal characteristics like character, behaviour, intelligence, preferences and talents; or characteristics concerning ethnical origin etc.

intervene with a harmonizing regulation which includes the use of genetic testing in sports as a special part in line with protection of human rights as also required by the Council of Europe.

Final remarks

In this paper I have discussed the current role of scientific and technological advances in sports following a human rights-based approach in relation to a specific phenomenon, namely genetic TI of athletes. I am conscious that this kind of approach is not a universal panacea. However, once one raises the ideal of organizing human coexistence based on human rights, a consistent implementation in the system must follow. And this concerns all fields of human activity playing a relevant role in society: sport is for sure one of these. To the extent that sport is recognized as a human right what is formally stated in rules ought to be practically applied if the system intends to be of any utility. And this is a matter of axiological consistency. Axiological inconsistency is indeed a problem because it goes to the heart of what protection based on human rights is for. This protection is for the benefit of all individuals including specific categories like athletes, especially when they belong to vulnerable subgroups like minors. If we agree that the human rights narrative has still an important role to play in our societies, we can also agree that it is this legal perspective that should shape the use of science and technology and not vice versa. It follows that even elite sport finds some limits to the use of what science and technology make available. With regard to the topic of our discussion, the respect for the dignity of the person and the right to freely construct one's personality should guide decisions on how to rule the use of genetic TI in sports including elite sport. In order to concrete implement these rights, Norberto Bobbio's suggestion that the law may play a 'promotional' function⁴⁰ aiming at stimulating desirable behaviours through positive sanctions can be transposed to sports. To award athletes, sports clubs, physicians, and trainers that make a sound ethical use of scientific and technological advances with subsidies, tax exemptions and the like could give a fillip to making sport really functional to achieving higher moral standards of decency and coexistence.

⁴⁰ N. BOBBIO, *Dalla Struttura alla Funzione*, Ed. Comunità, Milano, 1977.

