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# Regulating Genetic Discrimination in the European Union

## Pushing the EU into Unchartered Territory or Ushering in a New Genomic Era?

Aisling de Paor & Delia Ferri\*

### Abstract

*Against the backdrop of rapid developments in genetic science and technology, one of the main concerns arising in this area is the potential use of genetic testing to discriminate, especially in the employment and insurance contexts. Employers and insurance companies may use the results of genetic tests to discriminate (primarily for economic advantage), based on perceptions of future health risks or future disabilities. This article explores the scope for an EU to effectively address genetic discrimination and the misuse of genetic information. It first provides a theoretical overview of the choice of regulatory frameworks. It then examines the scope and protection of current non-discrimination laws in the EU and investigates the possibility of an EU level response to address the misuse of genetic information.*

**Keywords:** genetics, regulation, discrimination, data protection, European Union.

### A Introduction

In the last decade, genetic testing has become more sophisticated, more accessible, and therefore increasingly more widespread. Public attitudes towards genetic testing itself are generally positive,<sup>1</sup> since it allows diagnosis of inherited diseases and offers the potential to detect future disabilities. It is generally acknowledged that genetic science and technology has been displaying a great potential to prevent and treat illnesses.

Despite this welcoming attitude, concerns have constantly risen in relation to the potential breach of genetic privacy by interested third parties as a result of

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1 L. Henneman & I. Van Hoyweghen, 'Moving beyond Public Fear of Genetic Discrimination', Health and Ageing Newsletter 28, April 2013. Available at <[www.genevaassociation.org/media/77290/ga2013-health28-hennemanvan\\_hoyweghen.pdf](http://www.genevaassociation.org/media/77290/ga2013-health28-hennemanvan_hoyweghen.pdf)> (accessed 30 November 2013).

unauthorised access, disclosure, and use of such information.<sup>2</sup> In addition, the uneasy fear that genetic information can be misused to discriminate against a person is rapidly growing.<sup>3</sup> Non-governmental organisations (NGOs) as well as independent human rights actors often denounce the increased and actual risks of discrimination for individuals:<sup>4</sup> for example, in the United States, according to the Coalition for Genetic Fairness, employers have considered a genetic test as a predictor of the future health of an employee and of his/her level of future absenteeism or low work rate. The Coalition reported several cases of exclusion of job applicants on the basis of predicted future health.<sup>5</sup> The UK Human Genetics Commission (HGC)<sup>6</sup> in 2002 recommended that consideration needed to be given to specific legislation protecting people against discrimination on the basis of genetics, and most recently in 2011, it stated the necessity to monitor evidence of genetic discrimination and keep the need for legislative change under review.<sup>7</sup> Legal literature has expressed a major concern that genetic discrimination may leave a class of people who cannot work and are uninsurable.<sup>8</sup>

To address potential misuses of genetic information, a body of international soft and hard law documents on the use of genetic testing and emerging biotechnology techniques has been developed.<sup>9</sup> The most relevant example of international binding law is the European Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine (Oviedo Convention), approved by the Council of Europe in 1997, which bans all forms of discrimination based on a person's genetic features and allows predictive genetic tests only for health or scientific research purposes.<sup>10</sup> In

- 2 For further discussion see M. Taylor, *Genetic Data and the Law: A Critical Perspective on Privacy Protection*, Cambridge University Press 2012. See also G. Laurie, *Genetic Privacy: A Challenge to Medico – Legal Norms*, Cambridge University Press 2002.
- 3 E. Geelen *et al.*, 'Unravelling Fears of Genetic Discrimination: An Exploratory Study of Dutch HCM Families in an Era of Genetic Non-Discrimination Acts', *EJHG*, Vol. 20, 2012, pp. 1018-1023.
- 4 M. Otlowski *et al.*, 'Practices and Attitudes of Australian Employers in Relation to the Use of Genetic Information: Report on a National Study', *Comparative Labor Law and Policy Journal*, Vol. 31, 2009-2010, p. 637; A. de Paor, 'The Regulation of Genetic Information in Ireland – Does It Strike an Appropriate Balance of Rights?', *MLJI*, Vol. 19, No. 2, 2013, p. 97.
- 5 For further details see <[www.geneticfairness.org](http://www.geneticfairness.org)> (accessed 21 March 2014).
- 6 The HGC was established in 2000 to provide the UK Governments with advice on the ethical, legal, and social issues arising from Human Genetics and it adopted different approaches in various pieces of its work. It was disbanded in 2012.
- 7 HGC, *The Concept of Genetic Discrimination: A Seminar Report and Reflections and Recommendations 2011*, at <[www.cloisters.com/news-pdf-downloads/cathys-pdf.pdf](http://www.cloisters.com/news-pdf-downloads/cathys-pdf.pdf)>.
- 8 A. Somek, 'Genetic Discrimination', *Society*, 2003, p. 36. See also M.A. Rothstein & B. Knoppers, 'Legal Aspects of Genetics, Work and Insurance in North America and Europe', *EJHL*, Vol. 3, 1996, p. 143
- 9 T. Lemke, *Perspectives on Genetic Discrimination*, Routledge 2013.
- 10 C. Campiglio, 'Il principio di non discriminazione genetica nella recente prassi internazionale', *Diritti umani e diritto internazionale*, 2008, pp. 513-534; I.V. Motoc, 'The International Law of Genetic Discrimination: The Power of Never Again', in T. Murphy (Ed.), *New Technologies and Human Rights*, Oxford University Press 2009; J. Beqiraj, 'Prohibition of Genetic Discrimination: Applicative Perspectives under the Lens of Human Rights Protection', *La Comunità internazionale*, 2011, pp. 91-112.

addition, national legislation has been enacted as a reaction to the increasing fears about the misuse of genetic data and in order to protect people discriminated against on the ground of genetic information. The most significant example is the US Genetic Information Non-Discrimination Act (GINA), passed in 2008. Also, several European Member States have approved specific provisions to protect genetic data and, in some cases, to ban their discriminatory use.<sup>11</sup>

Within the European Union (EU), this scattered and dissimilar legislative response to questions of genetic privacy and genetic discrimination has resulted in a 'patchwork' of national legislative acts with no common ground. These different legislative approaches, focusing on the protection of access to and disclosure of an individual's genetic information or on the prevention of a discriminatory use of genetic data, still reflect national and cultural differences with regards to genetics, but also diverse social welfare systems.<sup>12</sup> Yet, there is a general perception that this legislative 'patchwork' is detrimental to the actual protection of EU citizens and is a threat to the principle of non-discrimination, which is deeply rooted in the EU legal order.

The need for an EU level response to the risk generated by the widespread use of genetic testing has been advocated for long. In 1989, the European Parliament called for an EU ban of the use of genetic testing in insurance matters to eliminate the risks of discrimination.<sup>13</sup> In 2003, the Group on Ethics in Science and

- 11 E. Stefanini, *Dati genetici e diritti fondamentali. Profili di diritto comparato ed europeo*, Cedam 2008; M.A. Rothstein & Y. Joly, 'Genetic Information and Insurance Underwriting: Contemporary Issues and Approaches in the Global Economy', in P. Atkinson *et al.* (Eds.), *Handbook of Genetics and Society: Mapping the New Genomic Era*, Routledge 2009; M.T. Annecca, 'Test Genetici e Diritti della Persona', in S. Canestrari *et al.* (Eds.), *Trattato di Biodiritto. Il Governo del Corpo*, Giuffrè 2011, pp. 391-422; Lemke 2013, p. 27; A. de Paor, 'US and EU Perspectives on Genetic Discrimination in Employment and Insurance: Striking a Balance in a Battlefield of Competing Rights?', in L. Waddington *et al.* (Eds.), *European Yearbook of Disability Law*, Vol. 4, Intersentia 2013, pp. 99-144. For example, the Belgian Law of 28 January 2003 prohibits the use of genetic testing and genetic screening in employment, and the subsequent law of 8 October 2004 prohibits discrimination on the ground of genetic data. In France, Law 2004-800 on bioethics allows for genetic tests only for health or scientific research purposes and the Code Penal prohibits discrimination on the ground of genetic features (Article 225, para. 1). In Italy, the privacy regulation (Legislative Decree 196/2003) allows for the use of genetic data only upon authorization of the National Privacy Authority. See M. Croce, 'Genetica umana e diritto: problemi e prospettive', *Jura Gentium Rivista di filosofia, del diritto internazionale e della politica globale* 2008. Available at <[www.juragentium.org/topics/rights/it/croce.htm](http://www.juragentium.org/topics/rights/it/croce.htm)> (access 30 November 2013); R. Lattanzi, 'Ricerca Genetica e Protezione dei Dati Personali', in Canestrari *et al.* 2011, pp. 319, 338. In the UK, people who have actual symptoms of a genetic disorder meet the definition of disabled and are covered by the Disability Discrimination Act (DDA), whilst people whose genetic data predict a later genetic disorder or a higher probability to a disease do not enjoy any legal protection. In Austria, Denmark, and The Netherlands, genetic testing for employment purposes is illegal. Part 4 of the Irish Disability Act 2005 regulates genetic testing in a number of third party contexts, including insurance, employment, and the mortgaging of property, by prohibiting the processing of genetic data in these contexts.
- 12 S. Soini, 'Genetic Testing Legislation in Western Europe – A Fluctuating Regulatory Target', *Journal of Community Genetics*, Vol. 3, 2012, p. 143. See also O. Varga *et al.*, 'Definitions of Genetic Testing in European Legal Documents', *Journal of Community Genetics*, Vol. 3, 2012, p. 125.
- 13 European Parliament's Resolution on the ethical and legal problems concerning genetic manipulation, 16 March 1989.

New Technologies (EGE) called for urgent EU action on genetic discrimination. Further, Article 21(1) of the EU Charter of Fundamental Rights specifically provides for, *inter alia*, 'genetic features' as a ground of discrimination.<sup>14</sup> However, at the time of the writing of this article, the EU has not legislated yet in this field. The proposal for a new non-discrimination directive, which is currently under discussion, does not mention genetic data, nor genetic discrimination. The EU is also currently engaged in a reform of legislation on data protection, which would introduce 'genetic data' among the categories of sensitive data,<sup>15</sup> but the entry into force of this reformed legal framework should not be expected too soon (despite the commitment of the new Juncker Commission, officially approved by the European Parliament on 22 October 2014).<sup>16</sup>

Against this background, this article critically discusses the desirability of EU legislation to ban genetic discrimination and the extent of EU competence to legislate in this field.

This article does not examine ethical issues related to genetic testing, nor the complex regulatory issues linked to genetic testing in the clinical setting. Nevertheless, before addressing the EU's role in protecting genetic data and prohibiting genetic discrimination, this article explores the merits of adopting a stand-alone legislative approach and briefly addresses the concept of 'genetic exceptionalism'.

This article is structured as follows. Following the introduction, Section B discusses, in a general fashion, the extent to which genetic discrimination is addressed in the current EU legal framework and tries to evaluate the 'gaps' of protection in the current legal framework. Section C addresses the desirability of an EU directive banning genetic discrimination and is divided into four subsections. First it examines the desirability of an *ad hoc* piece of legislation. Then it highlights the choice of regulatory frameworks in legal theory and discusses the meaningfulness of the non-discrimination approach. The fourth subsection of the Section C analyses the extent of EU competence to pass a new *ad hoc* non-discrimination genetic information directive. Section D formulates some tentative conclusions.

14 Charter of Fundamental Rights of the European Union officially proclaimed on 7 December 2000, Official Journal of the European Communities, 18 December 2000, [2000] OJ C 364/01, and now published on Official Journal of the European Union 26 October 2012 [2012] OJ C 326/391.

15 On 25 January 2012, the Commission adopted a package for reforming the European data protection framework, in order to modernise the EU legal system for the protection of personal data, to strengthen individuals' rights, and ensure a free flow of personal data within the EU, and to improve the clarity and coherence of the EU rules, in compliance with Art. 16 TFEU and Arts 7 and 8 of the EU Charter of Fundamental Rights (EU CFR). The package includes a 'Proposal for a Regulation on the protection of individuals with regard to the processing of personal data and on the free movement of such data' and a 'Proposal for a Directive on the protection of individuals with regard to the processing of personal data by competent authorities for the purposes of prevention, investigation, detection or prosecution of criminal offences or the execution of criminal penalties, and the free movement of such data'. The proposed regulation, which is currently under discussion, contains a definition of 'genetic data' in Article 4, and Article 9, building on Article 8 of the Directive 95/46/EC, specifically prohibits the processing of *inter alia* genetic data (although allowing for exceptions).

16 <[http://ec.europa.eu/about/juncker-commission/priorities/07/index\\_en.htm](http://ec.europa.eu/about/juncker-commission/priorities/07/index_en.htm)>.

## B Genetic Discrimination in the Current EU Legal Framework

### I The 'State of Art'

Before considering whether, why, and how the EU could enact legislation to address genetic discrimination, it is worth appraising the extent to which genetic discrimination is currently addressed in the EU legal framework.

In the EU constitutional framework, the principle of non-discrimination and equality is firmly embedded in the Treaties. Article 2 TEU on the values of the EU states that the Union is founded, *inter alia*, on equality, and that “[t]hese values are common to the Member States in a society in which pluralism, non-discrimination, tolerance, justice, solidarity and equality between women and men prevail”. Article 3 TEU states that the EU “shall combat social exclusion and discrimination”. Article 9 TEU mentions the equality of citizens in the European institutions, and Article 21 TEU sets forth the respect of the principle of equality in EU external action. Although these articles do not create any legal rights, their prominent position in the TEU shows that the EU is committed to ensure equality.<sup>17</sup> Article 10 TFEU contains a horizontal clause on non-discrimination<sup>18</sup> and provides the EU with a legal basis for the EU non-discrimination legislation. Article 19 TFEU (former Article 13 EC) allows the EU to take action to combat discrimination on the named grounds of sex, racial or ethnic origin, religion or belief, disability, age, or sexual orientation.

However, none of the Treaty provisions mention genetic data, nor health as grounds of discrimination. By contrast, ‘genetic features’ is included as a ground of discrimination in Article 21 EU CFR. The EU CFR establishes a right to equality before the law and a prohibition of discrimination on a wider list of grounds than Article 19 TFEU, and this list is extensive and open-ended, as will be clear from the words “any grounds such as”.<sup>19</sup> Nevertheless, as clarified in the Explanation of the Charter, Article 21 EU CFR does not create any power to enact anti-discrimination laws in the areas of competence of Member States, nor does it lay down a sweeping ban of discrimination in wide-ranging areas.

Having regard to secondary legislation, former Article 13 EC (*i.e.* Article 19 TFEU) has been the legal base for a second generation of equality directives (so-called ‘Article 13 Directives’), which build upon the experience gained in the legis-

17 E. Howard, ‘EU Equality Law: Three Recent Developments’, *ELJ*, Vol. 17, 2011, pp. 785-803; E. Ellis & P. Watson, *EU Anti-Discrimination Law*, Oxford University Press 2012.

18 Article 10 TFEU reads as follows: ‘[i]n defining and implementing its policies and activities, the Union shall aim to combat discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation’.

19 Howard 2011, p. 787.

lation to combat gender and other forms of discrimination at the EU level.<sup>20</sup> Among the non-discrimination instruments, the most relevant in this context and for the purpose of the subsequent analysis is the Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation ('Employment Equality Directive'). As provided for in Article 1 of this Employment Equality Directive, its purpose is

to lay down a general framework for combating discrimination on the grounds of religion or belief, disability, age or sexual orientation as regards employment and occupation, with a view to putting into effect in the Member States the principle of equal treatment.

There is a significant amount of literature on the Employment Equality Directive, and several CJEU's decisions have shaped the meaning and the scope of its provisions. For the purpose of this analysis, it suffices to point out that this directive bans both direct discrimination (differential treatment based on a specific characteristic) and indirect discrimination (any provision, criterion, or practice which is neutral on its face but is liable to adversely affect one or more specific individuals or incite discrimination). Settled CJEU case law states that the principle of non-discrimination requires that comparable situations must not be treated differently and that different situations must not be treated in the same way, and a different treatment may be justified only if it is based on objective considerations and only if it is proportionate to the legitimate objective being pursued.<sup>21</sup> Harassment, which creates a hostile environment, is also deemed to be discrimination. The Employment Equality Directive requires Member States to provide for effective judicial remedies, bestow representative associations with *locus standi* to bring actions on behalf of individuals, contain rules on the reversal proof, and provide for sanctions. Notably, the Employment Equality Directive imposes only minimum requirements and allows Member States to apply provisions which are more favourable to the protection of equal treatment, than those laid down in the Directive.

As it appears from Article 1, the Employment Equality Directive covers six grounds of discrimination, and it does not include genetic features among them. The question is provoked whether this missing ground is an obstacle to ensuring

20 These Directives include: Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation [2000] OJ L 303/16; Directive 2000/43/EC of 29 June 2000 implementing the principle of equal treatment between persons irrespective of racial or ethnic origin [2000] OJ L 180/22; Council Directive 2004/113/EC implementing the principle of equal treatment between men and women in the access to and supply of goods and services of 13 December 2004 [2004] OJ L; Directive 2006/54/EC of the EP and of the Council of 5 July 2006 on the implementation of the principle of equal opportunities and equal treatment of men and women in matters of employment and occupation (recast) [2006] OJ L 204/23.

21 Case C-148/02 *Carlos Garcia Avello v. Etat Belge* [2003] ECR I-11613.

protection from discrimination based solely on the nature of an individual's genotype.

It might be argued that a broad understanding of the concept of disability discrimination could also cover genetic discrimination. It is outside the scope of this article to explore the link between disability and genetics in depth: we limit ourselves to note that genetic testing can potentially predict a low or high probability of future disability or can predict that certain genotypes will indicate disability in the future. The Employment Equality Directive could accordingly cover under 'disability discrimination' and any other discrimination on the ground of the prediction of future illness or future loss of functions in a currently asymptomatic individual or on the ground of a genetic susceptibility to future health problems.

At present, there is no definition of disability in the Employment Equality Directive, nor in other pieces of legislation. Thus, there are no textual arguments against such a wide interpretation.

It is noted that this wide interpretation would be in line with Article 21 EU CFR, which by virtue of Article 6(1) TEU has a constitutional value. In addition, such an extensive interpretation would be in compliance with the UN Convention on the Rights of Persons with Disabilities (hereinafter 'the Convention' and the 'CRPD'), ratified by the EU by means of the Council decision of 26 November 2009.<sup>22</sup>

In this respect, it must be recalled that Article 1 CRPD states that

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

This is not a strict definition (it is placed in the article on 'Purpose' rather than under Article 2 on 'Definitions'), and it is non-exhaustive. This means that implementing legislation should treat disability as a socially constructed phenomenon and could include among disabled people short-term conditions but also genetic differences. Article 2 defines "Discrimination on the basis of disability" as follows:

any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation.

22 Council Decision 2010/48/EC, [2010] OJ L 23/35.

The quoted wide-ranging notion of discrimination covers not only persons with actual disabilities but also persons who, while not having a disability presently, might acquire a disability in the future or persons who simply are perceived as having a disability.

The CRPD currently enjoys a quasi-constitutional status in the EU legal system beneath the Treaties but above secondary law. As a consequence, EU secondary law must, so far as is possible, be interpreted in a manner that is consistent with the CRPD: if the wording of secondary EU legislation is open to more than one interpretation, preference should be given, as far as possible, to the interpretation which renders the European provision consistent with the Convention.<sup>23</sup> The CJEU has recognised the existence of this duty of consistent interpretation, by virtue of the 'sub-constitutional' rank of international agreements in the EU, independently of the direct effect of the international law provisions concerned.<sup>24</sup>

Up to now, the CJEU has not been confronted with any question regarding the potential of the Directive to be extended to genetic discrimination. However, the Court has released a few decisions on disability discrimination. In the absence of a legislative definition, the CJEU, at first,<sup>25</sup> had adopted a narrow concept of disability, based on the antiquated medical model of disability,<sup>26</sup> and had clearly distinguished sickness from disability.<sup>27</sup> In *Chacon Navas*, the Court clarified that fundamental rights which form an integral part of the general principles of EU law include the general principle of non-discrimination, but

23 Case C-61/94, *Commission v. Germany* [1996] ECR I-3989, para 52. See F. Casolari, 'Giving Indirect Effect to International Law within the EU Legal Order: The Doctrine of Consistent Interpretation', in E. Cannizzaro et al. (Eds.), *International Law as Law of the European Union*, Martinus Nijhoff 2011, pp. 394-422.

24 Case C-335/05, *Řízení Letového Provozu ČR, s. p. v. Bundesamt für Finanzen* [2007] ECR I-4307, para 52. Case 92/71, *Interfood GmbH v. Hauptzollamt Hamburg* [1972] ECR 231, para 6. See also D. Ferri, 'The Conclusion of the UN Convention on the Rights of Persons with Disabilities by the EC/EU: A Constitutional Perspective', in L. Waddington & G. Quinn (Eds.), *European Yearbook of Disability Law*, Vol. 2, Intersentia 2010, p. 47.

25 Case C-13/05, *Sonia Chacón Navas v. Eures Colectividades SA* [2006] ECR. I-6467.

26 The medical model tends to view persons with disabilities as objects who are to be managed or cared for, while the society emphasizes respect for the equal human rights of persons with disabilities. See C. Barnes & G. Mercer, *Exploring Disability*, Cambridge, Polity Press 2010.

As noted by Waddington, according to the CJEU the cause of the disadvantage is the 'impairment' which an individual has. Therefore, the problem lies in the impaired individual and not in the reaction of society to the impairment or the organization of society. This model can be contrasted with a social model of disability, which is reflected in the CRPD. The social model is based on a socio-political approach which argues that disability stems primarily from the failure of the social environment to adjust to the needs and aspirations of people with impairments. L. Waddington, 'Equal to the Task? Re-Examining EU Equality Law in Light of the United Nations Convention on the Rights of Persons with Disabilities', in Waddington et al. 2013, pp. 169-200.

27 L. Waddington, 'Case C-13/05, *Chacón Navas v. Eures Colectividades SA*, judgment of the Grand Chamber of 11 July 2006', *Common Market Law Review*, Vol. 44, No. 2, 2007, pp. 487-499.

it does not follow from this that the scope of Directive 2000/78 should be extended by analogy beyond the discrimination based on the grounds listed exhaustively in Article 1 thereof.

However, most recently, the CJEU has embraced a more wide-ranging definition of disability openly in line with Article 1 CRPD and reflective of the social model of disability.

In *Ring and Werge*,<sup>28</sup> the CJEU openly distanced itself from the position it took in *Chacon Navas* and interpreted the definition of disability in light of the CRPD. Another case, in line with *Ring and Werge*, is *Commission v. Italy*.<sup>29</sup> The case originated from action for failure to fulfil EU obligations brought by the Commission against Italy. The Commission affirmed that Italy did not correctly transpose Directive 2000/78 into its national law, and, in particular, it did not ensure, in breach of the Directive, that reasonable accommodation in the workplace is to apply to all persons with disabilities, all employers, and all aspects of the employment relationship. In its decision the CJEU confirmed that, while it is true that the concept of a 'disability' is not directly defined in the Employment Equality Directive, it should be interpreted on the basis of the CRPD. Most recently, in *Z. v. A Government Department and The Board of management of a community school*, the CJEU held that the CRPD "is capable of being relied on for the purposes of interpreting Directive 2000/78, which must, as far as possible, be interpreted in a manner that is consistent with that Convention".<sup>30</sup> The Court also confirmed that the concept of disability within the meaning of Directive 2000/78 had to be understood as referring to a limitation which results in particular from long-term physical, mental, or psychological impairments which in interaction with various barriers may hinder the full and effective participation of the person concerned in professional life on an equal basis with other workers.

Even though the CJEU has shown to embrace a relatively wide definition of disability, it has constantly held that

the scope of Directive 2000/78 cannot be extended beyond the discrimination based on the grounds listed exhaustively in Article 1 of the directive, with the result that a person who has been dismissed by his employer solely on account of sickness cannot fall within the scope of the general framework established by Directive 2000/78.<sup>31</sup>

We can conclude that 'genetic features' is a missing ground in the Employment Equality Directive (as well as in Article 19 TFEU). However, the particular cases of

28 Join cases C- 335/11 and C- 337/11, *HK Danmark, acting on behalf of Jette Ring v Dansk almennyttigt Boligselskab* (C-335/11) and *HK Danmark, acting on behalf of Lone Skouboe Werge v Dansk Arbejdsgiverforening, acting on behalf of Pro Display A/S, in liquidation* (C-337/11) 11 April 2013, not yet published.

29 Case C-312/11, *Commission v Italy*, 4 July 2013, not yet reported.

30 Case C-363/12 *Z. v A Government Department and The Board of management of a community school*, not yet published

31 Case C- 303/06 *Coleman v. Attridge Law and Steve Law* [2008] ECR I-5603.

*Ring and Werge* and *Commission v. Italy* leave the door open to the wide interpretation of the Employment Equality Directive in light of the CRPD to also cover genetic discrimination in the field of employment under disability discrimination.

## II *The Proposal for a New Non-Discrimination Directive: 'Old Wine in a New Bottle'*

Almost six years ago, in 2008, the Commission proposed a new Directive extending the material scope of the provisions against discrimination on the ground of religion and belief, disability, age, and sexual orientation beyond the area of employment in the fields of social protection, including social security and healthcare; social advantages; education; access to and supply of goods; and other services which are available to the public, including housing.<sup>32</sup> The proposed Directive replicates those parts of the material scope of the Race Equality Directive that were not included in the Employment Equality Directive. However, as noted by Howard, the scope is still less wide than that of the Race Directive, as Article 3 of the Proposal contains more exceptions.<sup>33</sup> Waddington, in her analysis of the proposal, underlines that many Member States are still querying the extent of the EU's power to legislate in areas such as health and social protection, and this makes the scope of the proposal blurred and still vague.

The original text of the proposal follows the pattern of the existing Directives, with few notable exceptions. For instance, as underlined by Bell, the most striking novelty lies in the definition of discrimination: the proposal conceptualises 'denial of reasonable accommodation' as a form of discrimination, in compliance with the CRPD.<sup>34</sup> However, the proposal as it stands does not mention genetic features and replicates the choice of the existing Directives in not providing any definition of the discrimination grounds. As recalled by Bell, this choice was particularly contested in relation to disability.<sup>35</sup>

The European Parliament released a 'Legislative Resolution to the Proposal' in which it proposes a number of amendments.<sup>36</sup> These include adding the reference to the fact that the Directive complies with the CRPD (Recital 2b of the Preamble) and a provision that would make clear that assumptive discrimination (*i.e.* discrimination against someone because the discriminator thinks they have a particular religion or belief, disability, age, or sexual orientation) is included (Article 4 para 4a). Another interesting amendment suggested by the European Parliament is to add to Article 4(1) of the Directive a sentence that makes it clear that

32 COM (2008) 426. M. Bell, *Anti-Discrimination Law and the European Union*, Oxford University Press 2005; L. Waddington, 'Future Prospects for EU Equality Law. Lessons to Be Learnt from the Proposed Equal Treatment Directive', *European Law Review*, Vol. 2, 2011, pp. 163-84; Ellis & Watson 2012, p. 372.

33 Howard 2011, pp. 785, 789.

34 M. Bell, 'Advancing EU Anti-Discrimination Law: The European Commission's 2008 Proposal for a New Directive', *Equal Rights Review*, Vol. 3, 2009, pp. 7-10.

35 *Ibid.*, p. 8.

36 P6\_TA(2009)0211 European Parliament Legislative Resolution of 2 April 2009 on the Proposal for a Council Directive Implementing the Principle of Equal Treatment between Person Irrespective of Religion or Belief, Disability, Age or Sexual Orientation (COM (2008)0426-C6-291 / 2008-2008/0140(CNS)).

'disability' is understood in the light of the CRPD, which includes persons with chronic diseases. However, no attempts to include genetic features as a ground of discrimination or to mention genetic discrimination have been made.

If approved as it stands, it is unlikely that the text will advance the protection of EU citizens from genetic discrimination. Genetic discrimination should be again covered under the umbrella concept of disability. Analogously, in the event the amendments proposed by the Parliament are approved, no clear protection against a more disadvantageous treatment on the sole ground of genetic data is given. The direct reference to the CRPD could favour the extensive interpretation of the ground of disability, and the inclusion of a provision on assumptive discrimination could also facilitate the protection against genetic discrimination, given that the discriminatory treatment is based on perceived – not actual – disability. But, again, in any event, a key role will be left to the CJEU.

Finally, even if the Court ruled that genetic discrimination would be covered by the Directive, the text (as it stands now) contains an exception which is likely to hamper protection in the insurance context. Article 2(7) authorises "proportionate differences in treatment" in financial services, provided that "age or disability is a key factor in the assessment of risk based on relevant and accurate actuarial or statistical data". In the explanatory memorandum, the Commission argues that "the use of age or disability by insurers and banks to assess the risk profile of customers does not necessarily represent discrimination: it depends on the product". This wording, at least potentially, could be used to allow insurance companies to charge individuals different rates or vary coverage based on genetic predisposition, or even to discourage some at-risk individuals from getting an insurance contract.

It is too soon to formulate any concluding remarks on this proposal. At this stage, it is fairly unclear whether and when the text will be adopted. Even less clear is whether the text will be modified again by the Council, whether any of the amendments proposed by the Parliament will be approved and implemented in the final text. The proposed directive has been examined in the Council for more than four years now, and discussion is still needed on a number of issues, such as the division of competences, the overall scope and subsidiarity, and the disability provisions. Future debates could hopefully bring some developments in the text. Although the inclusion of genetic features as ground of discrimination seems quite challenging, the provision on assumptive discrimination proposed by the Parliament could be made clearer and more explicit.

However, even in the best-case scenario, the proposed Directive appears inadequate to address and prevent the misuse of genetic data outside the employment context.

## **C The Way Forward: A New EU *ad hoc* Directive?**

### *I Filling in the Gaps?*

Currently the EU does not provide any satisfactory protection against the misuse of genetic information: there is no concrete protection against genetic discrimina-

tion in the employment context, and there is actually no defense outside the employment context. As mentioned above, there is currently a reform process taking place in the EU in the area of data protection law, and there is a new non-discrimination directive under discussion. However, none of them address genetic discrimination.

Having highlighted the inadequacy of the current legal framework, the question on whether or not the EU should adopt a specific regulation to combat and prevent the misuse (or discriminatory use) of genetic data is linked to three main issues: first, the desirability and the appropriateness of an ad hoc legislative instrument, second, the desirability of non-discriminatory approach, and, third and more specifically, the feasibility of an EU genetic-discrimination directive.

## II 'Genetic Exceptionalism': Some Theoretical Considerations

The desirability of an *ad hoc* piece of legislation is based on the very nature of genetic data and on its difference in comparison to other types of data, which is commonly known as 'genetic exceptionalism'.<sup>37</sup>

'Genetic exceptionalism' was first advanced by Thomas Murray, who based his reflection upon the concept of 'HIV Exceptionalism', which viewed HIV as exceptional, based on the potential for discrimination and stigmatisation.<sup>38</sup> Against the backdrop of advancing technology, genetic exceptionalism conceives genetic information as deserving special non-discrimination, privacy protections (or other protections), in light of the fact that it is inherently unique and different from other forms of personal or health information. Although this view has been contested,<sup>39</sup> we contend that there are several reasons to embrace it.

Firstly, it is commonly acknowledged that genetic data uniquely identifies an individual, and such information can reveal a myriad of personal details, including current and (potential) future health status, physical appearance, as well as behavioural and other traits.<sup>40</sup> As Somek states, "[i]f there is anything special about our genes, from a sociological perspective, then it is the potential to make known, possibly, the naked truth about our present condition and our future destiny". Even if we reject the idea of mere 'genetic determinism', or the concept that our genes exclusively predict individual fate and are an individual's 'future diary',

37 See generally T.H. Murray, 'Genetic Exceptionalism and "Future Diaries": Is Genetic Information Different from Other Medical Information?', in M.A. Rothstein (Ed.), *Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic*, Yale University Press 1997. See also G.J. Annas, 'Genetic Privacy: There Ought to Be a Law', *Texas Review of Law and Policy*, Vol. 4, 1999, pp. 9-11. For further discussion see M.A. Rothstein, 'Genetic Exceptionalism and Legislative Pragmatism', *JLME*, 2007, p. 59; C.S. Diver & J.M. Cohen, 'Genophobia: What Is Wrong with Genetic Discrimination?', *University of Pennsylvania Law Review*, Vol. 149, 2000-2001, p. 1439.

38 Murray 1997; R. Bayer, 'Public Health Policy and the AIDs Epidemic: An End to HIV Exceptionalism?', *NEJM*, Vol. 324, 1991, pp. 1500-1504.

39 M.A. Rothstein, 'Genetic Exceptionalism and Legislative Pragmatism', *Hastings Center Report*, No. 4, 2005, pp. 27-33; S. Suter, 'The Allure and Peril of Genetics Exceptionalism: Do We Need Special Genetics Legislation?', *Washington University Law Quarterly*, Vol. 79, No. 3, 2001, p. 669.

40 G. Laurie, 'The Most Personal Information of All: An Appraisal of Genetic Privacy in the Shadow of the Human Genome Project', *International Journal of Law, Policy and Family*, Vol. 10, 1996, pp. 74-101.

it appears generally acknowledged that genetic information effectively “informs our younger selves about our aging selves”.<sup>41</sup>

Secondly, genetic information is different from other medical information, in that it reveals sensitive information not only about an individual but also about that individual’s relatives. The familial nature of genetic information necessarily gives rise to additional considerations in relation to privacy, for example, in the context of reproduction.<sup>42</sup>

Another unique element of genetic information relates to the fact that it is immutable.<sup>43</sup> In addition to the unique nature of genetic data, another reason in support of genetic exceptionalism relates to the stigma associated with genetic information. Legal scholarship has noted often that the misuse of genetic information has led to discrimination, eugenics, and, in certain circumstances, has exacerbated racism.<sup>44</sup> In light of this stigma attached to genetic predisposition to disease and genetic conditions, discrimination or other misuse of genetic information should be specifically prohibited. Although a detailed discussion of this argument is outside the scope of this article, it suffices to point out that, in the absence of explicit protections, this may lead to the practice of genetic cleansing and the potential relegation of what are deemed to be genetically undesirable individuals.<sup>45</sup>

Another (perhaps less convincing) reason in favour of singling out genetic information and genetic discrimination in the regulation relates to the expressive value of the law.<sup>46</sup> Although this is primarily a rhetoric argument, it acknowledges the merit of a specific body of law acting as a tool to engrain a strong moral message in society that a certain practice or behaviour is wrong and will not be tolerated.

Each of the above arguments, taken individually, may not necessarily carry significant weight.<sup>47</sup> However, collectively they formulate a strong case in favour of genetic exceptionalism and a genetic-specific approach in addressing the regulation of this area.

- 41 Annas 1999, pp. 9-11. Annas uses the analogy of genetic information as a “future diary” which he takes from William Safire’s explanation of diaries, which “inform our aging selves about our younger selves”. W. Safire, ‘Sleazy Senate Inquiry’, *New York Times*, 25 October 1993, p. 19.
- 42 A. Somerville & V. English, ‘Genetic Privacy: Orthodoxy or Oxymoron?’, *JME*, Vol. 25, 1999, pp. 144-145.
- 43 Suter 2001, pp. 669-706.
- 44 K.L. Garver & B. Garver, ‘The Human Genome Project and Eugenic Concerns’, *American Journal of Human Genetics*, Vol. 54, 1994, p. 148; L.B. Andrews, ‘Past as Prologue: Sobering Thoughts on Genetic Enthusiasm’, *Seton Hall Law Review*, Vol. 27, 1997, p. 893.
- 45 D. Hellman, ‘What Makes Genetic Discrimination Exceptional?’, in V. Gehring (Ed.), *Genetic Prospects: Essays on Biotechnology, Ethics and Public Policy*, Rowman and Littlefield 2003, pp. 90-91.
- 46 A. de Paor, ‘Regulating Genetic Information – Exploring the Options in Legal Theory’, *EJHL*, Vol. 21, 2014, pp. 425-453.
- 47 L.P. Francis, ‘You Are Born with Your Genes: Justice and Protection against Discrimination in the Use of Genetic Information’, *Mount Sinai Journal of Medicine*, Vol. 77, No. 2, 2010, pp. 188-190.

### III *The Desirability of a Non-Discrimination Approach*

Having discussed the desirability of an *ad hoc* piece of legislation, the question on whether the EU should ban genetic discrimination is linked to the desirability and appropriateness of a non-discrimination regulatory approach as a type of normative intervention that is ultimately most likely to promote virtuous behaviour and discourage undesirable practices in third party contexts such as employment, as well as in society in general.

Genetic discrimination has been defined as the unjustified unequal treatment of persons owing to their genetic characteristics.<sup>48</sup> When investigating genetic discrimination, it has been often acknowledged that the main areas of interest are screening and diagnostic testing and that the danger is that different genetic features emerging from the testing might be interpreted as defining different 'kinds' of people and as defining different 'values' of people. Genetic discrimination is most likely to take the form of disadvantages in employment<sup>49</sup> and increase of premium or indeed denial of insurance coverage.<sup>50</sup> The protection of genetic data, *i.e.* a privacy approach, which aims to protect access to and disclosure of an individual's genetic information, seems insufficient to prevent these discriminatory uses of genetic information. While privacy ensures security and confidentiality in both information and personal space and safeguards the dignity and integrity of individuals by protecting that which is considered important and private, a 'privacy approach' in itself does not prevent the potential that the individual may be treated in a more disadvantageous way than another comparable individual "solely or primarily because of his/her genotype or because of a specific genetic defect, without there being a sufficient and reasonable justification for such disadvantageous treatment".<sup>51</sup>

Privacy laws generally operate by requiring consent from the relevant party to access or control his/her genetic information. Third parties can access such information by way of obtaining consent from the individual in question. Simi-

48 J. Gerards, 'General Issues Concerning Genetic Information', in J.H. Gerards, A.W. Heringa & H.L. Janssen (Eds.), *Genetic Discrimination and Genetic Privacy in a Comparative Perspective*, Intersentia 2005, p. 24.

49 Stefanini 2008; A. Trojsi, 'Biodiritto del lavoro' e tutela antidiscriminatoria: i Dati genetici del lavoratore', 2009. Available at <[www.biodiritto.org/images/progetto/TROJSI.pdf](http://www.biodiritto.org/images/progetto/TROJSI.pdf)> (accessed 30 November 2013); Lemke 2013.

50 T. Lemke, 'Beyond Genetic Discrimination. Problems and Perspectives of a Contested Notion', *Genomics, Society and Policy*, 2005, pp. 22-40; M. Viola de Azevedo Cunha, *Market Integration through Data Protection: An Analysis of the Insurance and Financial Industries in the EU*, Springer 2013; E.A. Adjin-Tettey, 'Potential for Genetic Discrimination in Access to Insurance: Is There a Dark Side to Increased Availability of Genetic Information?', *Alberta Law Review*, Vol. 50, No. 3, 2013, p. 577.

Another relevant field in which the use of genetic data is relevant is the forensic science and the criminal procedure filed, but this is outside the scope of this paper. See L. Scaffardi, 'Legal Protection and Ethical Management of Genetic Databases: Challenges of the European Process of Harmonization', *Jean Monnet Working Papers*, 2008. Available at <[www.astrid-online.it/Documenti/Privacy/estratto-scaffardi-new-york.pdf](http://www.astrid-online.it/Documenti/Privacy/estratto-scaffardi-new-york.pdf)> (accessed 10 March 2014). G. Barbujani & F. Tassi, 'Genetic Data in Forensic Science: Use, Misuse and Abuse', in R. Bin & N. Lucchi (Eds.), *Biotech Innovations and Fundamental Rights*, Springer 2012, pp. 243-260.

51 Gerards 2005, p. 24.

larly, the individual may refuse to consent in which case the third party cannot access the information.<sup>52</sup> However, the discriminatory use of genetic data might happen in several different circumstances: for example, where an employer, insurer, or other third party inadvertently comes across details of an individual's genetic information, for example, through a family member's obituary in a newspaper, through other publically available resources, or through casual conversation with an individual; or where an individual has disclosed or has been obliged to disclose his/her genetic information; where the individual consents to the disclosure of genetic information; or where such disclosure may be lawful in the employment context for health and safety purposes.

The use of a non-discrimination approach to address the regulation of genetic information may encompass unfavourable treatment on the basis of perceived disability or perceived genetic defects to protect individuals against genetic discrimination, as well as to prevent the creation of a genetic underclass. From an individual perspective, non-discrimination law is therefore concerned with addressing unfavourable or unfair treatment, for example, on the basis of one's genetic information. From a societal perspective, the non-discrimination framework aims to address power relations and structural inequities in society.<sup>53</sup> As a result of societal inequities and structures, certain dominant groups may be the primary recipients of equality and fundamental rights while certain minority groups may encounter barriers to accessing fundamental human rights and equality.<sup>54</sup> In the current debate, the non-discrimination tool may operate to prevent the creation of a genetic underclass (and the relegation of genetically undesirable individuals) and deter the practice of genetic cleansing in society.

#### IV Is the EU Competent to Act?

Having discussed the theoretical desirability of genetic discrimination legislation, the most relevant and indeed most challenging question in this respect is whether the EU actually has the competence to adopt such a specific piece of legislation.

From 1997 (when former Article 13 EC was added), the EU has acquired a solid cross-cutting competence on non-discrimination on different grounds, in addition to the nationality and sex one which affirmed first.<sup>55</sup> As mentioned above, the TFEU contains a horizontal clause on non-discrimination in Article 10 TFEU and provides the EU with a legal basis for EU non-discrimination legislation. However, EU action can only be taken in those areas which fall within the limits of the powers conferred by the Treaty. Even though "what falls within the

52 J. Roberts, 'The Genetic Information Nondiscrimination Act as an Antidiscrimination Law', *Notre Dame Law Review*, Vol. 86, No. 2, 2011, p. 617.

53 A. Hendriks, 'The UN Disability Convention and (Multiple) Discrimination: Should EU Non-Discrimination Law Be Modelled Accordingly?', in Quinn & Waddington 2010, p. 10.

54 *Ibid.*, p. 10. See also G. Quinn, 'Disability Discrimination Law in the EU', in H. Meenan (Ed.), *Equality Law in an Enlarged European Union – Understanding the Article 13 Directives*, Cambridge University Press 2007, pp. 243-246.

55 E. Ellis, *EU Anti-Discrimination Law*, Oxford University Press 2005; D. Martin, *Egalité et non-discrimination dans la jurisprudence communautaire*, Buylant 2006.

scope of EU law differs depending on the context and on what idea the scope of EU law is based”<sup>56</sup> roughly speaking, we can state that employment and insurance fall within the scope of EU powers.<sup>57</sup>

It is noted that Article 19 TFEU, which is the legal basis for non-discrimination acts, does not mention ‘genetic information’ or ‘health’ as a prohibited ground.

The modification of Article 19 TFEU to include a new ground of discrimination is to be excluded since the procedure set forth in Article 48 TEU would be long and complex. As underlined in Section 4 with regard to the Employment Equality Directive, there would be the possibility that discrimination on grounds of genetic makeup is covered by the wider ground of (future) disability.<sup>58</sup> Whilst such a wide interpretation might be almost ‘taken for given’ with regard to the Directive, having regard to the latest CJEU’s decision, it should not be expected too easily in regard to Article 19 TFEU. There is no obligation to interpret the Treaties in light of the CRPD. This is evident *inter alia* in *Microsoft*,<sup>59</sup> when the Court of First Instance rejected the argument of the applicant, according to which former Article 82 EC (now Article 102 TFEU) had to be interpreted in the light of the TRIPS Agreement. The Court held

that the principle of consistent interpretation [...] invoked by the Court of Justice applies only where the international agreement at issue prevails over the provision of Community law concerned. Since an international agreement [...] does not prevail over primary Community law, that principle does not apply where, as here, the provision which falls to be interpreted is Article 82 EC.

However, the conclusion of the CRPD by the EU provides an added dimension to the debate of regulating genetic information and arguably acts as an impetus to action in this area and as an international standard from which to view the issue of disability discrimination.<sup>60</sup> In addition, Article 19 TFEU might be a suitable

56 M. Derlén & J. Lindholm, ‘Three Ideas: The Scope of EU Law Protecting against Discrimination’, in M. Derlén & J. Lindholm (Eds.), *Volume in Honor of Pär Hallström Uppsala*, Iustus 2012, pp. 77-97. Available: <<http://ssrn.com/abstract=2114247>> (accessed 30 November 2013).

57 The EU has a shared competence in the field of employment (covering freedom of movement, equal treatment, working conditions, including working time, part-time and fixed-term work, and posting of workers, information and consultation of workers, including in the event of collective redundancies and transfers of undertakings) and has also a solid competence in the field of insurance within the realisation of the internal market (freedom of movement of services and capitals). Currently, the TFEU considers insurance in Article 58 para. 2 (liberalisation of banking and insurance). Article 58 para 2 reads as follows: “The liberalisation of banking and insurance services connected with movements of capital shall be effected in step with the liberalisation of movement of capital.”

58 J. Gerards & H. Janssen, ‘Regulation of Genetic and Other Health Information in a Comparative Perspective’, *EJHL*, Vol. 13, 2006, pp. 372-374.

59 Case T-201/04, *Microsoft Corp. v. Commission* [2007] E.C.R. II-3601 [798].

60 A. de Paor, ‘US and EU Perspectives on Genetic Discrimination in Employment and Insurance: Striking a Balance in a Battlefield of Competing Rights?’, in Waddington *et al.* 2013, p. 143.

legal basis for a directive on genetic discrimination if its content is interpreted in light of Article 21 EU CFR. Although the Charter does not alter the extent of powers granted under Article 19 TFEU, it has, by virtue of Article 6(1) TEU, the same legal value as the Treaties. As a consequence, respect for fundamental rights is a legal requirement, subject to the scrutiny of the CJEU, and a condition of the lawfulness of EU acts.<sup>61</sup> The Commission in its Strategy on Smart Regulation<sup>62</sup> and in the Communication on Strategy for the effective implementation of the Charter of Fundamental Rights<sup>63</sup> affirmed that the Charter should be taken into account throughout the policy cycle. Again, the CJEU would play a vital role in enforcing the potential of the Charter in the protection of EU citizens from genetic discrimination. As highlighted by Howard, in line with other scholars,

although the Charter does not create new rights, both the way the Charter itself is interpreted by the Court of Justice and the way this Court could use it to interpret other provisions of EU law could extend the existing rights and the protection against discrimination in new directions.<sup>64</sup>

It seems that Article 19 TFEU read in conjunction with Article 21 EU CFR and the CRPD could certainly be an appropriate legal base for a new ad hoc piece of legislation.

In case of a directive on non-discrimination on grounds of genetic data, a double legal basis could also offer a viable solution. It is worth recalling that the choice of the legal base for a measure may not depend simply on an institution's conviction as to the objective pursued but must be based on objective factors which are amenable to judicial review.<sup>65</sup> In general, if an EU measure has more than one purpose and one of the purposes can be identified as the main or predominant purpose, then that measure must be adopted on the legal base corresponding with that main purpose. Only exceptionally, when a measure has more than one purpose without one being secondary, it can be based on more than one legal base ('dual legal base').

A well-tailored piece of legislation banning genetic discrimination in the fields of employment and access to goods and services would create a level playing field on the use of genetic information by business operators. In doing so, it would enhance the functioning of the internal market. Therefore, together with Article 19 TFEU, an additional legal basis could be found in Article 114 TFEU (which aims to ensure the effective functioning of the internal market in the EU). Article 114 previously acted as the legal basis for various pieces of legislation which include a disability dimension, and also the concluding decision of the CRPD was based on both Article 19 and 114 TFEU (former Article 13 and 95

61 Joined Cases C-92/09 and C-93/09, *Völker und Markus Schecke and Eifert* [2010] ECR I-11063.

62 COM(2010) 543 final.

63 COM(2010) 573 final.

64 Howard 2011, pp. 785-803; Ellis & Watson 2012.

65 Case C-11/88, *Commission of the European Communities v. Council of the European Communities*, [1989] ECR 3799.

EC).<sup>66</sup> The latter example, in particular, might offer an influential precedent and inspire a double-based proposal.

## D Conclusion

A wide range of genetic technologies are becoming increasingly more accessible, offering growing health benefits, but also presenting complex ethical and legal challenges. One of the emerging 21st-century challenges is deciphering the appropriate mode and means of regulating this area. “Genetics is intrinsically normative” and “tells us what to expect and what not to expect under given circumstances”, but “this should not dictate the values we should endorse”,<sup>67</sup> which should be protected by an appropriate legislative response. Such a response should prevent the abuse of genetic technologies, which would ultimately lead to the violation of a myriad of human rights whilst allowing the advance of genetic science.

In the early 1990s, legal scholarship (particularly in the United States) had already indicated that the use of genetic tests could lead to discrimination based solely on the nature of an individual’s genotype.<sup>68</sup> But in addition to the academic discourse, there has been a growing awareness that the spread of genetic testing brings with it the risk of discrimination.<sup>69</sup> Around the beginning of the 21st century, national laws were passed to prevent genetic discrimination in some of the EU Member States, but no action was taken by the EU.

Even by exploiting the potential of interpretation of existing legislation by including discrimination on grounds of genetic makeup in the wider ground of (future) disability, the Employment Equality Directive offers a low degree of protection due to its limited scope. The 2008 Proposal for a New Equality Directive ignores genetic discrimination and provides very little innovation in this regard. Hence, even if approved (and this result cannot be taken for granted), the text hypothetically offers poor safeguard.

Although further analysis, discussion, and debate of this issue is required amongst the relevant stakeholders, policymakers, and other interested groups, the preferable way forward appears a new single ground directive to ban any disadvantageous treatment of an individual based solely or primarily because of his/her genotype or because of a specific genetic defect. The EU has competence to legislate, in line with its commitment to equality, to ensure an internal market without any barriers, in line with the EU Charter of Fundamental Rights, as well as with international obligations the EU has engaged in. The potential for a dual legal basis for action in this field, which would highlight the objective of promoting the economic aims of the Union, enhance the operation of the internal mar-

66 Council Decision 2010/48/EC of 26 November 2009 concerning the conclusion, by the European Community of the United Nations Convention on the Rights of Persons with Disabilities [2010] OJ L 23/35.

67 HGC, *supra* n. 7.

68 *Inter alia*, L.O. Gostin, ‘Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers’, *AJLM*, Vol. 17, Nos. 1 & 2, 1991, p. 109.

69 Rothstein & Knoppers 1996, pp. 143-161.

ket, and address the issue of discrimination and the objective of equality for all citizens, seems to (at least potentially) mitigate the risk that some Member States question the EU competence. In any event, the adoption of a specific legislation seems the preferable avenue to pursue in order for the EU to usher in the new era of genetic evolution.