



Submission to the National Disability Authority
Review of the Operation of Part 4 of the Disability
Act 2005 (Genetic Testing)

Dr Aisling de Paor

11 November 2014

Review of the Operation of Part 4 of the Disability Act 2005 (Genetic Testing)

Consultation Feedback Form

The National Disability Authority has been requested to conduct a review of the operation of Part 4 of the Disability Act 2005 (Genetic Testing), by the Minister for Justice, Equality and Defence, as required under Section 44 of the Act.

We are conducting this consultation to hear what you think about the operation of Part 4 of the Disability Act 2005 (Genetic Testing). Your comments and feedback will be used to inform the final report on the review.

The closing date for submitting comments to us is **11th November 2014 at 5pm.**

- You can email your consultation feedback to:
genetictesting@nda.ie
- You can post your consultation feedback to:

Ruth O'Reilly,

Part 4 Review Consultation,

National Disability Authority,

25 Clyde Road,

Dublin 4.

- If you have any questions, you can contact Ruth O'Reilly by email at rcoreilly@nda.ie or by telephone at (01) 6080489.

Short Guide to Part 4 of the Disability Act 2005¹

Part 4 of the Disability Act provides safeguards for the use of information obtained from genetic testing. The provisions aim to ensure that people who may be affected by genetic disorders will not be subject to any unreasonable requirements from an employer or an insurance or mortgage provider. The protections provided are in addition to substantial safeguards for the use of personal information contained in the Data Protection Acts.

The safeguards provide that:

- genetic testing may only take place with a person's consent, in accordance with the Data Protection Acts
- the results of a genetic test can't be used in relation to insurance, a mortgage, a personal pension or employment
- the person being tested must be made aware of the intended use of the test results and must, as far as possible, be informed about the possible outcomes of the test
- the use of a person's family history for insurance purposes may be regulated by the Minister after consultation with other relevant Ministers, the Data Protection Commissioner and other interested bodies or groups

Part 4 came into operation on 31 December, 2005.

¹ Department of Justice, Equality and Law Reform, 2006, **Guide to the Disability Act**, accessed 22nd July 2014, Department of Justice and Equality, <<http://www.justice.ie/en/JELR/DisabilityAct05Guide.pdf/Files/DisabilityAct05Guide.pdf>>

1. Your details

Note: It is intended to publish a list of the respondents who make submissions in response to this consultation on the NDA website. It is NOT necessary for you to complete this section, if you do not wish to do so.

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If commenting on behalf of an organisation, what is the name of the organisation?

Socio- Legal Research Centre, School of Law and Government,
Dublin City University

2. General Feedback

Please provide general feedback on the operation of Part 4 of the Act in response to the questions below.

2.1 In your opinion, what is working well with the operation of Part 4 of the Act?

Please comment here.

In comparison with other jurisdictions that have not yet legislated,² Irish law in this area has made some tangible steps in the right direction and the inclusion of these provisions in the Disability Act 2005 was a positive first step in addressing this field.

The number of third party contexts covered by the Irish legislation in this area is relatively comprehensive and Part 4 regulates genetic testing in a number of third party contexts, including insurance, employment, pensions and the mortgaging of property, prohibiting the processing of genetic data in these contexts. Although Part 4 therefore has a relatively broad scope of protection, it is acknowledged that there are additional contexts where misuse of genetic information may take place, including immigration, sport, and reproduction, as well as in a variety of commercial settings.

In terms of the regulatory model adopted, Ireland takes primarily a privacy/ data protection approach. The aim of this model is to protect the privacy of genetic information – to protect access to and disclosure of genetic information. From a privacy/ data protection perspective, the provisions are welcomed and offer some level of protection, with the effect of controlling the flow of genetic information and requiring the consent of the individual for use of genetic information.

² For example, the United Kingdom has not yet introduced any specific legislative provisions in this area. Although it is noted that the United Kingdom has a high profile moratorium in place between the Association of British Insurers and the Department of Health, known as the Concordat and Moratorium on Genetics and Insurance (first established in 2001).

2.2 In your opinion, what is not working well with the operation of Part 4 of the Act?

Please comment here.

Although Part 4 offers welcomed protections against misuse of genetic information, certain shortcomings can be identified.

Ireland takes a 'non- genetic specific' approach and Part 4 is therefore arguably hidden away in the Disability Act. The absence of a stand- alone piece of legislation may result in a general lack of awareness of the legal provisions in place. Linked to this, the absence of a stand- alone piece of legislation may not carry the expressive value desirable in such a novel and sensitive area, where the potential for misuse of genetic information is significant. See 3.2 below.

Although Part 4 contains relatively strong privacy/ data protection provisions, there is a lack of non- discrimination protections. This is undesirable in light of the potential for the discriminatory use of genetic information in a variety of third party contexts including employment and insurance. In order for individuals to be fully protected against misuse of genetic information, it is necessary to have non- discrimination provisions. In addition, the absence of non- discrimination provisions in this area may ultimately expose a large proportion of the population with putative disabilities. This may act to further set back the inclusion of persons with disabilities in society and create unjust barriers to accessing a wide range of social goods and services. See 3.2 below.

There is a lack of clarity in the definitions contained in Part 4 (section 41). The ambiguity and uncertainty in the framing of the definitions may lead to conflicting interpretations as well as confusion in the application and effect of the provisions. See 3.1 below.

There are currently no protections in Part 4 for the disclosure and use of family medical history information. This needs to be addressed. See 3.1 and 3.3 below.

The absence of any empirical evidence in this area presents challenges in ascertaining the effectiveness of the provisions and the practical impact of Part 4. See 3.2 below.

2.3 If you have suggestions or recommendations in relation to the operation of Part 4 of the Act, please provide them below.

Please comment here.

Stand- alone legislation

In consideration of the shortcomings of Ireland's 'non- genetic specific' approach, it is suggested that there is a need for a 'genetic specific' stand-alone regulatory framework in this field.

The merits of a 'genetic specific,' stand- alone regulatory framework in this field are recognised. Such a framework would be specifically tailored to the issues in question. It may also offer the opportunity to remove some of the ambiguity existing in the current framework. A stand- alone regulatory framework reflects the theory of genetic exceptionalism.³ This theory recognises the unique and special nature of genetic information. Such an approach would single out genetic information as deserving of special protections and would thereby carry a useful expressive value.

A genetic exceptionalism approach is reflected in some of the responses amongst the EU Member States (including Germany,⁴ Portugal,⁵ and Austria⁶), as well as the approach in other jurisdictions, such as the United States.⁷

It is submitted that it is now necessary to stand back from piecemeal legislation to craft a much more rounded approach to the issue of genetics and the law. This is happening elsewhere and Ireland is potentially at risk of falling behind.

Dual approach

³ Thomas H. Murray, 'Genetic Exceptionalism and 'Future Diaries': Is Genetic Information Different from Other Medical Information?' in Mark A Rothstein (ed) *Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era* (Yale University Press 1997); Sonia Suter, 'The Allure and Peril of Genetic Exceptionalism: Do we need Genetic Specific Legislation?' (2001) 79 *Washington University Law Quarterly* 3 669

⁴ Human Genetic Examination Act (Genetic Diagnosis Act GenDG) 374/09, 2009

⁵ Personal Genetic Information and Health Information Act, Law No. 12/2005 of 26 January 2005

⁶ Gene Technology Act-GTG (Gentechnikgesetzes BGBl 510/1994)

⁷ Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110- 233, 122 Stat. 881 (2008) ("GINA")

Certain shortcomings with a discrete privacy/ data protection approach can be pointed out. Privacy does not provide for the continuing protection or control of personal information once it is in the public sphere. This creates the possibility of misuse of this information once it is in the public sphere, perhaps leading to the discriminatory use of the information. Accordingly, the privacy regime does not protect against the discriminatory use of genetic, (or other personal) information.⁸ Similarly, it is observed that a privacy regime alone often does not address the potential use of genetic information obtained through other means – for example, through an individual's inadvertent disclosure of family history or genetic information obtained through publically available sources, such as an obituary or through social media.

It is also observed that as science advances and as genetic information becomes more appealing to third parties, it will become more routinely sought after in application forms and other scenarios (such as in employment and insurance). In these circumstances, individuals may be aware of their right to privacy, but in practical terms may feel obliged or even forced to reveal such information.⁹ Individuals may feel that for professional reasons, it is necessary to agree to disclosure to comply with such requests. Further, if individuals refuse to disclose such information, an employer or other third party may nevertheless mistreat the individual, or raise negative assumptions as to an individual's perceived genetic status.¹⁰

Considering the evident shortcomings, it is clear that the privacy framework alone can only reach so far and there are gaps that can be identified that cast doubt as to whether such a regime would operate to fully protect genetic information or instill the necessary confidence in individuals. The shortcomings with the privacy/ data protection framework compel the need for additional protections and perhaps a complementary non- discrimination approach. Similarly, it is submitted that protecting genetic information through a non- discrimination approach alone may not be adequate to fully protect and prevent misuse.¹¹

⁸ Janneke Gerards, 'General Issues concerning Genetic Information' in Janneke Gerards, Aart Heringa and Heleen Janssen (eds) *Genetic Discrimination and Genetic Privacy in a Comparative Perspective* (Intersentia 2005) 23

⁹ Jessica Roberts, 'The Genetic Information Nondiscrimination Act as an Antidiscrimination Law (2011) 86 *Notre Dame Law Review* 2 597, 618

¹⁰ *Ibid*

¹¹ Pauline T. Kim, 'Genetic Discrimination, Genetic Privacy: Rethinking Employee Protections for a Brave New Workplace' (2002) 96 *Northwestern University Law Review* 1497, 1498

It is suggested that the preferable approach in this area is utilisation of both the non- discrimination approach and the privacy/ data protection approach, as a two- pronged mechanism for ensuring the full protection of genetic information. Such a framework would ensure that access to and disclosure of genetic information is controlled and would ensure that the discriminatory use of genetic information is prohibited.

In consideration of the unique and sensitive nature of genetic information, it is observed that such a comprehensive legislative framework is preferable and arguably necessary in order to ensure the protection of fundamental human rights and instill confidence in individuals that genetic technologies can be used to enhance health care without the fear that it will be used to disadvantage and segregate.

An incentive for reform comes in the shape of the EU Charter of Fundamental Rights which, expressly prohibits discrimination based on genetic features. Article 21.1 of the EU Charter of Fundamental Rights, prohibits discrimination based on, *inter alia*, genetic features, thereby singling out genetic discrimination as a priority area of reform.¹² This provision highlights the need for non- discrimination provisions in this area, to protect against the discriminatory use of genetic information.

From a transatlantic perspective, and in highlighting the use of non- discrimination provisions in this field, it is noted that the United States passed the landmark Genetic Information Non Discrimination Act (GINA 2008), a federal level law which prohibits the misuse of genetic information by employers and health insurers. Reference is also made to the German legislation which utilises primarily non- discrimination provisions in controlling genetic information. An example of a ‘dual approach’ of utilising both non- discrimination and privacy provisions is evident in the Portuguese approach.

At an international level, the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD)¹³ is a key legal instrument in this area. The UN CRPD demands enhanced protection for privacy as well as non-discrimination, and this instrument may be used as an impetus to action and reform in this area. Ireland has signed the UN CRPD with a view to ratifying.

¹² Charter of Fundamental Rights of the European Union, 7 December 2000, Official Journal of the European Communities, 18 December 2000 (2000/C 364/01), Article 21.1

¹³ United Nations Convention on the Rights of Persons with Disabilities (2006) G. A. Res 61/106 (“UN CRPD”)

Awareness raising

It is arguable that the provisions in Part 4 are 'hidden away' in the Disability Act 2005. This inevitably gives rise to a general lack of awareness of the protections available, which certainly dilutes the effectiveness of the legislative provisions.

In addition to legislative endeavours, it is recommended that there is also a need to consider an awareness raising and educational campaign, to target medical professionals, commercial entities and other third parties, as well as the general public. It is submitted that there is a need to raise awareness and educate as to the benefits (and limitations) of genetic science and technology, the potential for misuse of such technology, as well as the legal protections in place. In support of this point, it is noted that a number of international legal instruments (including the UN CRPD¹⁴) similarly provide for such awareness raising and education.¹⁵

In the absence of appropriate awareness raising in this area, there is a real possibility that individuals, interested third parties, as well as the public in general will be unaware of genetics and the potential of genetic technologies, as well as being unaware of the legal protections in place. For individuals, this may result in a fear of misuse of genetic information as well as a lack confidence in availing of emerging genetic technologies. Third parties such as insurance companies and employers may be unsure of their obligations regarding individuals' genetic information and there is an increased potential for such information to be misused.

Empirical evidence

There is an absence of empirical data gathered in this area in Ireland (and indeed in Europe in general) indicating evidence of genetic discrimination, evidence of fear of genetic discrimination, or other misuse of genetic information including privacy violations. This makes it very challenging to assess the effectiveness of the legal protections in place in Part 4, and challenging to ascertain the particular nature of the issues to be addressed.

It is recommended that there is the need to engage in empirical research to provide further details, insight and evidence of the incidence of genetic

¹⁴ UN CRPD, Article 8.

¹⁵ For example, International Declaration on Human Genetic Data 2003, Article 24; Universal Declaration on Bioethics and Human Rights 2005, Article 25

discrimination, breach of genetic privacy and other misuse of genetic information. In support of this recommendation, reference is made to the United States and Australia where studies have been carried out which illustrate the reality of genetic discrimination and other issues arising from misuse of genetic information.¹⁶ In particular, Australia has been a leader in carrying out a major multidisciplinary national level study to investigate the incidence of genetic discrimination from various perspectives.¹⁷ This study was successful in providing valuable information and evidence of the nature and effect of misusing genetic information. The Australian Law Reform Commission also carried out a significant investigation into this area, which complemented the empirical study carried out.¹⁸

Ireland can certainly learn from these international endeavours, both as an indication of similar misuse here, as well as a potential impetus to engage in the required empirical investigation in this area. In Ireland, such research would inform and support any legislative and policy endeavours. With reference to the Australian project, it is recommended that any proposed empirical research project take a multifaceted approach to this area, and consider the perspective of all relevant stakeholders including scientists, commercial entities and the public.

Balance of rights

An individual's right of privacy in genetic information – or one's right to the non-discriminatory use of the information – has to be carefully balanced against the potentially legitimate 'right to know' (of whatever weight or

¹⁶ Billings et al, '*Discrimination as a consequence of genetic testing*' (1992) 50 *American Journal of Human Genetics* 476, Geller et al, '*Individual, family and societal dimension of genetic: A case study analysis*' (1996) 2 *Science and Engineering Ethics* 1 71, Lapham et al, '*Genetic Discrimination: Perspectives of Consumers*', (1996) 274 *Science* 621, Otlowski et al, '*Genetic Discrimination: International Perspectives*' (2012) 13 *Annual Review of Genomics and Human Genetics* 433

¹⁷ For further details see www.gdproject.org See also Otlowski et al, '*Major study commencing into genetic discrimination in Australia*' (2002) 10 *Journal of Law and Medicine* 41; Taylor et al, '*Investigating Genetic Discrimination in Australia: opportunities and challenges in the early stages*' (2004) 23 *New Genetics and Society* 2 225, 227; Taylor et al, '*Investigating Genetic Discrimination in Australia: Perceptions and Experiences of Clinical Genetics Service Clients Regarding Coercion to Test, Insurance and Employment*' (2007) 5 *Australian Journal of Emerging Technologies and Society* 2 63; Otlowski et al, '*Investigating Genetic Discrimination in the Australian Life Insurance Sector: Use of Genetic Test Results in Underwriting (1999- 2003)*' 14 *Journal of Law and Medicine* 367; Otlowski et al, '*Practices and Attitudes of Australian Employers in relation to the use of genetic information: Report on a National Study*' (2009- 2010) 31 *Comparative Labor Law and Policy Journal* 637,

¹⁸ Australian Law Reform Commission, *Essentially Yours: The Protection of Human Genetic Information in Australia* (ALRC 96, 2003)

scope) of third parties such as employers, insurers and potentially the State. This calls for a very careful and thoughtful balancing of competing rights and interests.

There is an absence of exceptions in Part 4. There a need for more carefully crafted exceptions in the Irish regulatory framework in this area, providing details of the circumstances in which use of genetic information may be permitted by third parties, to reflect commercial interests in this area and potentially legitimate competing rights. Reference is made to the US legislation, GINA, which contains a number of well-balanced exceptions, highlighting the limited 'right to know' of third parties in certain restricted circumstances. In Europe, the German legislation also contains some similar exceptions.

It is submitted that the inclusion of any such exceptions in the Irish legislative framework requires additonal discussion, analysis and consultation with all of the relevant stakeholders in this field.



3. Specific Feedback

Please comment on specific operational issues related to each Section of Part 4 of the Disability Act in the relevant boxes below. The text of each section is provided for reference.

3.1 Section 41, Interpretation:

- In this Part –

‘the Acts’ means the Data Protection Acts 1988 and 2003;

‘genetic data’ means data relating to a living person derived from genetic testing of the person;

‘genetic testing’ means the examination of samples taken from a living person for the purpose of analysing the person’s deoxyribonucleic or ribonucleic acid by means of chromosomal analysis or by any other means for the purpose of –

- (a) confirming the identity or nature of an existing symptomatic disease,
- (b) ascertaining whether the person has a genetic predisposition or susceptibility to a disease, or
- (c) identifying the carrier of a disease;

‘processing’ has the meaning assigned to it by the Acts.

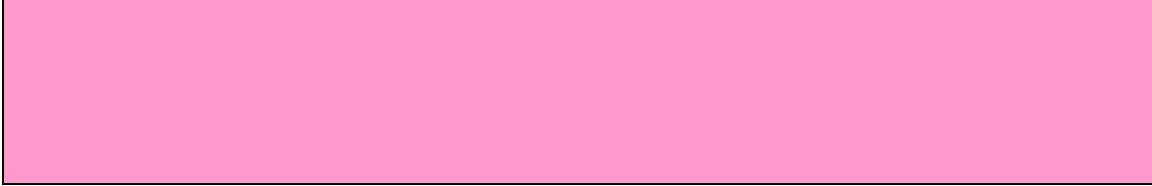
Please comment here on Section 41.

As regards the definitions contained in Section 41, there is an overall lack of clarity, which creates ambiguity and confusion in relation to the operation and effect of the provisions in Part 4.

In particular, there is ambiguity as regards what constitutes ‘genetic testing.’ For example, the phrase ‘by any other means’ is ambiguous, overly broad and likely to give rise to confusion. The definition of ‘genetic testing’ needs to be clarified and updated, particularly in consideration of the speed at which science and technology is advancing. In this regard, there is a need for active engagement with geneticists, and other scientists specialised in genetics and related new technologies.

The scope of the definitions in Section 41 needs to be addressed. The definition of ‘genetic data’ can be criticised as being too narrow, particularly considering that family medical history information is not included within this definition (either explicitly or by implication). Family medical history

information should be included within the definition of genetic information/
data, or at least be provided for separately in the legislation.



3.2 Section 42, Genetic testing and processing of genetic data

42. – (1) Genetic testing shall not be carried out by a person unless -

- (a) the testing is not prohibited by law, and
- (b) the consent of the person to the processing of any genetic data to be derived from the testing has been obtained in accordance with the Acts.

(2) A person shall not engage in the processing of genetic data in relation to –

- (a) the employment of a person save in accordance with the provisions of section 12A of the Data Protection Act 1988 (as inserted by the Data Protection (Amendment) Act 2003),
- (b) a policy of insurance or life assurance,
- (c) a policy of health insurance or health-related insurance,
- (d) an occupational pension, a retirement annuity contract or any other pension arrangement,
- (e) the mortgaging of property.

(3) A person shall not process genetic data unless all reasonable steps have been taken to provide the data subject with all appropriate information concerning –

- (a) the purpose and possible outcomes of the proposed processing, and
- (b) any potential implications for the health of the data subject which may become known as a result of the processing.

(4) A person who contravenes subsection (2) or (3) shall be guilty of an offence; an offence under this subsection shall be deemed to be an offence to which section 31 of the Data Protection Act 1998 applies.

Please comment here on Section 42.

Section 42 provides that the informed consent of the data subject is required in respect of the processing of genetic data, thereby highlighting a privacy/ data protection approach. It provides that the processing of genetic data is prohibited in relation to a policy of assurance, a policy of health insurance or health related product, an occupational pension, a retirement annuity contract or any other pension arrangement, unless the consent of the person has been obtained in accordance with the Acts. In the insurance context, an insurer therefore cannot request, take into

account or process the results of genetic tests, (as defined in section 41).¹⁹ It is effectively an exception to the traditional duty of full disclosure of material facts, which is an established practice in the insurance industry. Although, these provisions highlight a reasonably strong privacy/ data protection approach across a broad spectrum, with a focus on controlling the flow of genetic information, there are no protections against the discriminatory use of genetic data.

In addition, it is currently not prohibited for insurance companies to ask whether an insurance applicant has had a genetic test. Insurance companies should not be permitted to ask an applicant whether he/she has had a genetic test. Insurance companies may make inferences from such answers, which may negatively impact insurance applicants and their families, creating barriers in accessing insurance.

In the employment context, section 42 of the 2005 Act provides that it is an offence to process genetic data for employment under the Data Protection Acts 1998 and 2003. By virtue of the Data Protection (Processing of Genetic Data) Regulations 2007²⁰ the processing of genetic data concerning the employment of a person is a prescribed activity for the purposes of Section 12A of the Data Protection Acts 1988 to 2003. It provides that the use of genetic testing or genetic data of employees requires the prior consent of the Data Protection Commissioner. It is noted that no such request has yet been made to the Data Protection Commissioner (which may arguably be as a result of a general lack of awareness). These Regulations provide welcomed safeguards, from a privacy/ data protection perspective. However, there are no non-discrimination protections. It is submitted that such non-discrimination provisions are necessary in the employment context, particularly given the potential for misuse and the importance of preventing any unjust employment barriers.

Finally, it is noted that the wording of section 42 (in particular, section 42 (1)) is ambiguous and is likely to lead to confusion, as well as potentially conflicting interpretations. The “double- negative” contained in section 42 (1) is misleading and it needs to be clarified.

¹⁹ Irish Insurance Federation, Annual Report (2006) p 17

²⁰ Data Protection (Processing of Genetic Data) Regulations 2007 (S.I. No. 687 of 2007)



3.3 Section 43, Family History Information

43. – (1) Information about the family history of an applicant for insurance may be processed in accordance with such regulations (if any) as may be made by the Minister under section 2B(1)(b)(xi) of the Data Protection Act 1988 (as inserted by the Data Protection (Amendment) Act 2003).

(2) Before making regulations referred to in subsection (1) the Minister shall consult –

(a) in relation to processing connected with health or health-related insurance (other than health or health-related insurance provided for under the Health Insurance Acts 1994 and 2003) with the Minister for Health and Children and the Data Protection Commissioner,

(b) in relation to processing connected with an occupational pension, a retirement annuity contract or any other pension arrangement, with the Minister for Social and Family Affairs and the Data Protection Commissioner,

(c) in relation to processing connected with policies of insurance, or life assurance (other than those specified in paragraph (a)), or a mortgage, with the Irish Financial Services Regulatory Authority and the Data Protection Commissioner.

(3) Before making regulations referred to in subsection (1) the Minister may consult with such other bodies or persons as he or she thinks fit.

Please comment here on Section 43.

Section 43 (1) states that information about the family history of an applicant for insurance shall be processed in accordance with such regulations (if any) as made by the Minister under section 2B(1)(b)(xi) of the Data Protection Act 1988 (as inserted by the Data Protection (Amendment) Act 2003). To date, no such Regulations have been introduced and there are no protections in Irish law for disclosure of family medical history.

Insurance companies generally request family medical history for underwriting purposes, for example in the field of life insurance.²¹ Use of family medical history by third parties (including insurance companies) potentially gives rise to privacy issues, as well as discrimination, with undesirable implications for an individual and one's relatives.

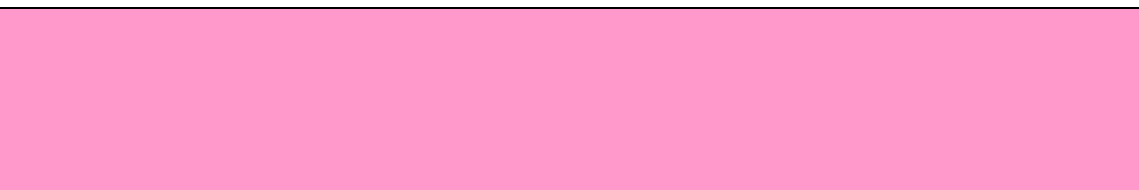
²¹ Irish Insurance Federation, Annual Report (2006) p 17

In the insurance context, it is recognised that family medical history is becoming more of a concern as science advances and greater links are made between genes and disease.²² It is inevitable that family members are going to become increasingly aware of their genetic make- up, creating a greater potential for discrimination and other misuse. Particular concerns might arise in circumstances where an individual's family members have tested positive for a certain genetic mutation. For example, an individual's mother or sister may have tested positive for the BRCA1 or BRCA2 gene and this family history information is still accessible to insurers.²³ Insurers may well use this information and make certain inferences from the information, even if the individual in question does not have the genetic mutation.

Similarly, family medical history may also be used and misused in the employment context. This concern is evident for example from a case reported from Germany in 2006 which concerned a female German teacher who was discriminated against in her employment as a result of a family history of Huntington's disease.²⁴ As genetic science advances further, this problem is likely to become more apparent. It is therefore necessary that there are appropriate safeguards in place.

Although there is a lack of solid and reliable empirical evidence, there has been some anecdotal evidence in Ireland, particularly from patient group organisations (for example, the Genetic and Rare Disorder Organisation (GRDO)) illustrating the use and misuse of family medical history leading to discrimination, as well as other mistreatment and isolation in society.

It is recommended that family medical history information should be included within the definition of genetic information/ data, or at least be provided for in the legislation. See 3.1 above.



²² Van Hoyweghen, 'Your genes in insurance: from genetic discrimination to genomic solidarity' (2012) 9 Personalized Medicine 8 871, 873

²³ Madden, *Medicine, Ethics and the Law* (2nd Edn., 2011) 313

²⁴ Schmitz and Wiesing, 'Just a Family Medical History?' (2006) 332 British Medical Journal 297. See also Burgermeister, 'Teacher was refused job because relatives have Huntington's disease' (2003) 327 British Medical Journal 827

3.4 Section 44, Review of operation of this Part

44. – (1) The Minister shall initiate, not later than 1 January 2014, a review of the operation of this Part and shall ensure that the review is carried out.

(2) The person carrying out a review under subsection (1) shall consult with such other Ministers of the Government as he or she considers appropriate, the Data Protection Commissioner, the Irish Financial Services Regulatory Authority and such other persons or bodies as he or she considers appropriate.

Please comment here on Section 44.

Section 44 of the Disability Act provides that the Minister shall initiate, not later than 1 January 2014, a review of the operation of this Part.

This review is currently taking place. However, even with this review there is a potential that Ireland's legal provisions will remain patchy and disconnected. The Disability Act 2005 was formulated long before the GINA legislation in the United States, the recent national approaches in some of the EU Member States and the UN Convention on the Rights of Persons with Disabilities and it needs to be looked at again from a broader and international perspective.

3.5 Section 45, Saver

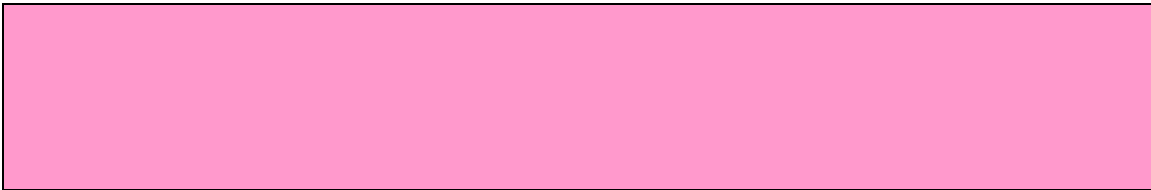
45. – (1) Nothing in this Part shall be construed as authorising the processing of personal data contrary to the provisions of the Data Protection Acts 1998 and 2003.

(2) Nothing in this Part shall be construed as prohibiting the taking and use in accordance with law of bodily samples for the purpose of forensic testing or analysis in connection with the investigation of an offence, or for any other purpose not prohibited by law, by or on behalf of the Garda Síochána or the processing by them of genetic data (if any) derived from such testing or analysis.

Please comment here on Section 45.

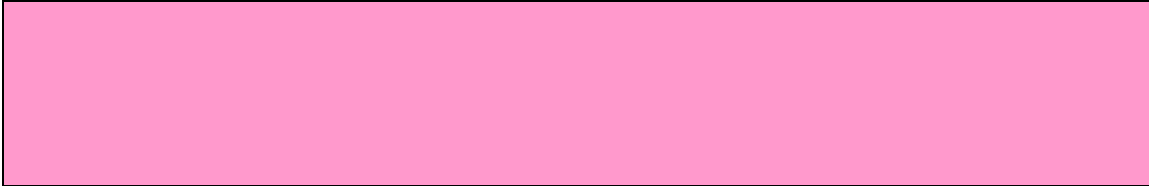
Section 45 (1) reaffirms the primacy of the provisions under the Data Protection Acts 1988 and 2003. It is noted that there is currently a reform process taking place in the EU regarding the EU data protection framework which will be implemented into Irish law (if and when it is introduced).

Section 45 (2) facilitates the use of bodily samples for forensic testing or analysis. It is suggested that this section be clarified to ensure that an individual's (as well as an individual's family member's) rights are upheld. In this regard, reference is also made to the recent introduction of the Criminal Justice (Forensic Evidence and DNA Database System) Act 2014.



4. Freedom of Information

All submissions are subject to the Freedom of Information Acts. If any of the detail you have provided us with is sensitive (on the basis that it is personal, confidential, or commercially confidential) please identify it in the box below and give reasons why you think it should not be released.



The NDA, where possible, will consult with you about any information which you have identified as sensitive information, before making a decision in response to a request for release under the Freedom of Information Acts. If you have any questions about this please contact the NDA's Freedom of Information Officer, Edward Crean at ecrean@nda.ie or by calling (01) 6080402.

Thank you for participating in the Review of the Operation of Part 4 of the Disability Act 2005 (Genetic Testing)