

Special section: GINA at 10 years

Disparate impacts and GINA: Congress's unfinished business

Jennifer K. Wagner*

Center for Translational Bioethics & Health Care Policy, Geisinger Health System, 100 N. Academy Ave., MC 30-42, Danville, PA 17822 USA

Corresponding author. E-mail: jwagner1@geisinger.edu

ABSTRACT

The Genetic Information Nondiscrimination Act of 2008 (GINA) deviated from preceding employment discrimination laws by excluding disparate impact liability, an important enforcement component to promote substantive equality. Nevertheless, Congress did not intend for this to be a permanent exclusion and, instead, assigned itself future work: after six years, a commission was to educate Congress on genetic discrimination incidents, update Congress on relevant scientific advances in genetics/omics, and provide recommendations to Congress on the need to enable disparate impact liability. Ten years after GINA became law, it seems appropriate to take a look back at the broader employment law context within which Congress made this decision to exclude disparate impact liability for genetic discrimination, explore how and why Section 208 became inserted into GINA, and provide a status update on the additional policy work mandated. After reasonable investigation, there is no information to indicate that Congress fulfilled its

* Jennifer K. Wagner is an Assistant Professor in the Center for Translational Bioethics & Health Care Policy and the Associate Director of Bioethics Research for Geisinger Health System as well as a solo practicing attorney. Dr. Wagner earned her J.D. at the University of North Carolina School of Law and her Ph.D. in Anthropology at the Pennsylvania State University before completing post-doctoral appointments at Duke University and the University of Pennsylvania. She is a member of several professional organizations, including the American Association for the Advancement of Science, American Society of Human Genetics (ASHG), American Association of Physical Anthropologists (AAPA), American Association of Anthropological Genetics, Centre County Bar Association, Pennsylvania Bar Association, and American Bar Association. She is the 2018 and 2019 chair of the ASHG Social Issues Committee and a member of the AAPA Ethics and Science Policy Committees. Her research focuses on anthropology, genetics, law, and policy.

© The Author(s) 2019. Published by Oxford University Press on behalf of Duke University School of Law, Harvard Law School, Oxford University Press, and Stanford Law School. This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs licence (http://creativecommons.org/licenses/by-nc-nd/4.0/), which permits non-commercial reproduction and distribution of the work, in any medium, provided the original work is not altered or transformed in any way, and that the work is properly cited. For commercial re-use, please contact journals.permissions@oup.com

statutory obligation to appoint members to a Genetic Nondiscrimination Study Commission or that any policy work envisioned by Section 208 has commenced. To fulfill a promise of fairness and equality, Congress must revisit the issue and enable disparate impact liability to value genetic diversity and prevent any 'genetic underclasses' from forming.

KEYWORDS: genetic information nondiscrimination act, discrimination, legislative history, ELSI, fairness, human rights

The Genetic Information Nondiscrimination Act of 2008¹ (GINA) protects individuals from genetic discrimination in health insurance and employment contexts. Within GINA's employment-related provisions is Section 208, which is an express limitation of liability on the basis of genetic information to disparate treatment claims, meaning that claims based on disparate impact theory are not permitted.² Congress did not intend for this to be a permanent exclusion without further consideration, however. Instead, GINA provided that an eight-member commission to be known as the 'Genetic Nondiscrimination Study Commission' was to be empaneled on six years following the passage of the law to 'review the developing science of genetics and to make recommendations to Congress regarding whether to provide a disparate impact cause of action under this Act. The composition of the study commission was also set by statute (presumably to ensure, at least in spirit, bipartisanship), with the Majority and Minority Leaders of the Senate, the House Speaker and Minority Leader, the HELP Committee Chair and Ranking Member, and the Chairman and Ranking Minority Member of the Committee on Education and Labor in the House of Representatives each entitled and obligated to appoint one member. ⁴ The commission was to complete its work and deliver a report within one year.

BACKGROUND ON EMPLOYMENT DISCRIMINATION, DISPARATE IMPACT LIABILITY, AND EQUALITY

The broader context⁵ of employment discrimination law and the American legal system's approach to equality within which GINA was enacted is useful for understanding

Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110–233, 122 Stat. 881 (2008), codified at 42 U.S.C. § 2000ff–2000ff-11.

² 42 U.S.C. § 2000ff–7.

³ Id.

^{4 14}

See eg Jack M. Balkin & Reva B. Siegel, The American Civil Rights Tradition: Anticlassification or Antisubordination?, 58 U. MIAMI L. REV. 9 (2003); Robert Belton, The Civil Rights Act of 1991: Unraveling the Controversy, 45 RUTGERS L. REV. 921 (1993); Stephanie Bornstein, Reckless Discrimination, 105 Cal. L. REV. 1055 (2017); Justin D. Cummins & Beth Belle Isle, Toward Systemic Equality: Reinvigorating a Progressive Application of the Disparate Impact Doctrine, 43 MITCHELL HAMLINE L. REV. 102 (2017); D. Wendy Greene, Categorically Black, White, or Wrong: 'Misperception Discrimination' and the State of Title VII Protection, 47 U. MICH. J. L. REFORM. 87 (2013); Helen Norton, The Supreme Court's Post-Racial Turn Towards a Zero-Sum Understanding of Equality, 52 WM.& MARY L. REV. 197, 207 (2010); Lawrence Rosenthal, Saving Disparate Impact, 34 CARDOZO L. REV. 2157 (2013); Reva B. Siegel, Equality Talk: Antisubordination and Anticlassification Values in Constitutional Struggles over Brown, 117 HARV. L. REV. 1470 (2004); Reva B. Siegel, Race-Conscious But Race-Neutral: The Constitutionality of Disparate Impact in the Roberts Court, 66 Ala. L. REV. 653 (2015); Michelle A. Travis, Toward Positive Equality: Taking the Disparate Impact Out of Disparate Impact Theory, 16 Lewis & Clark L. REV. 527 (2012).

how and why GINA's disparate impact liability exclusion is both significant and a serious legislative shortcoming.⁶ Prior to GINA, employment nondiscrimination was advanced via Title VII of the Civil Rights Act of 1964 (Title VII), Age Discrimination in Employment Act of 1967 (ADEA),8 and the Americans with Disabilities Act (ADA).9

Claims for unfair employment discrimination under Title VII¹⁰ may be brought under theories of disparate treatment and disparate impacts. 11 In 1971 the Supreme Court clarified in *Griggs v Duke Power Co.* that Congress had intended for Title VII to stop 'not only overt discrimination but also practices that are fair in form, but discriminatory in operation'. 12 Similar burden-shifting frameworks are used to prove claims based on disparate treatment¹³ or disparate impact.¹⁴ When an employee makes a *prima facie* case of disparate impact discrimination, the employer may avoid liability if the challenged practice or policy is 'job related' and consistent with a 'business necessity' (ie there is no alternative policy or practice available that could, without the discriminatory effects, achieve the employer's legitimate goals¹⁵). During the Reagan administration and with the reshaped Supreme Court in the 1980s, disparate impact theory was weakened, ¹⁶ and Congress specifically responded to the judicial activism with passage of the Civil Rights Act of 1991 to clarify its enduring intent to prohibit both forms of discrimination.¹⁷ In 1994, during the Clinton administration, the Attorney General¹⁸ issued a memo to all administrative agencies explaining,

Enforcement of the disparate impact provisions is an essential component of an effective civil rights compliance program... Facially neutral policies and practices that act as arbi-

- See generally Ifeoma Ajunwa, Genetic Data and Civil Rights, 51 HARV. C.R.-C.L. L. REV. 75 (2016); Bradley A. Areheart, The Anticlassification Turn in Employment Discrimination, 63 ALA. L. REV. 955 (2012); Bradley A. Areheart, GINA, Privacy, and Antisubordination, 46 GA. L. REV. 705 (2012); Jared A. Feldman & Richard J. Katz, Genetic Testing & Discrimination in Employment: Recommending a Uniform Statutory Approach, 19 HOFS-TRA L. & EMP. L. J. 389 (2003); Pauline T. Kim, Regulating the Use of Genetic Information: Perspectives from the U.S. Experience, 31 COMP. LAB. L. & POL'Y J. 693 (2010); Anya E. R. Prince, Comprehensive Protection of Genetic Information, 79 BROOKLYN L. REV. 175-225 (2013); Jessica L. Roberts, Protecting Privacy to Prevent Discrimination, 56 Wm. & Mary L. Rev. 2097 (2015); Jessica L. Roberts, The Genetic Information Nondiscrimination Act as an Antidiscrimination Law, 86 NOTRE DAME L. REV. 597 (2011); and Jessica L. Roberts, Preempting Discrimination: Lessons from the Genetic Information Nondiscrimination Act, 63 VAND. L. REV. 439 (2010).
- Civil Rights Act of 1964, Pub. L. No. 88-352, 78 Stat. 241 (1964) (codified as amended at 42 U.S.C. §2000e-2(k).
- Age Discrimination in Employment Act of 1967, Pub. L. No. 90-202, 81 Stat. 602 (1967) (codified as amended at 29 U.S.C. §§621-34).
- Americans with Disabilities Act of 1990, Pub. L. No. 101-336, 104 Stat. 327 (1990) (codified at 42 U.S.C. §12101–12117).
- Supra note 7.
- 11 Disparate impact liability is also available under the Americans with Disabilities Act and Age Discrimination in Employment Act, although the ADEA did not have an express disparate impact provision.
- ¹² Griggs v. Duke Power Co., 401 U.S. 424, 432 (1971)
- ¹³ McDonnell Douglas Corp. v. Green, 411 U.S. 792, 798 (1973).
- ¹⁴ Albemarle Paper Co v. Moody, 422 U.S. 405 (1975)
- In Ricci v. Stefano, 557 U.S. 557, 589 (2009), the Court went further to require this alternative must be an 'equally valid, less-discriminatory' one). See also Rosenthal, supra note 5.
- See eg Watson v. Fort Worth Bank & Trust, 487 U.S. 977 (1988); Wards Cove Packing Co v Atonio, 490 U.S. 642 (1989).
- Civil Rights Act of 1991, Pub. L. No. 102-166, 105 Stat. 1071 (1991).
- Janet Reno was the United States Attorney General in 1994.

trary and unnecessary barriers to equal opportunity must end. This was the goal...when it became law and it remains one of the highest priorities of this Administration. ¹⁹

Twenty-six administrative agencies have regulations addressing disparate impacts (for Title VI of the Civil Rights Act of 1964), 20 but Court decisions in the 2000s further undermined enforcement efforts²¹ making it increasingly difficult for disparate impact claims to be successful.

Opponents have produced 'manufactured tension' between disparate treatment and disparate impact theories. 22 This tension—pitting disparate treatment, framed as intentional and direct discrimination, against disparate impacts, framed as unintentional and merely indirect effects—is, in part, due to varying conceptualizations of equality itself.²³ Under formal equality, differences are to be disregarded and treatment the same. Accordingly, formal equality focuses on an anticlassification principle. Because any classification or deviation from same treatment is considered suspect, a formal model of equality makes it difficult to impose any remedial measures, such as affirmative action. One scholar has lamented, 'adherence to formal equality has seemingly eclipsed our moral and political aspirations for social justice'. 24 Others have described formal equality as necessary but insufficient²⁵ and 'an empty vessel that other normative values must 'fill' by dictating which traits to forbid'.²⁶

Under substantive equality, however, the fundamental principle is nonsubordination.²⁷ Ignoring differences (rather than valuing difference) is seen a shortcoming of formal equality, as treating differently situated individuals the same could perpetuate inequality rather than remedy it. Substantive equality models, thus, would have the law question the basis of perceived sameness and difference so that appropriate inclusionary, antidiscrimination measures can be taken in any given

Attorney General. Memorandum for Heads of Departments and Agencies That Provide Federal Financial Assistance. Subject: Use of the Disparate Impact Standard in Administrative Regulations Under Title VI of the Civil Rights Act of 1964. July 14, 1994. https://www.justice.gov/archives/ag/ attorney-general-july-14-1994-memorandum-use-disparate-impact-standard-administrative-regulations (last accessed July 30, 2018).

 $^{^{20}}$ U.S. Department of Justice, Civil Rights Division, Title VI Legal Manual: Section VII: Proving Discrimination - Disparate Impact. https://www.justice.gov/crt/case-document/file/923556/download (last accessed July 30, 2018. See also footnote 3 at https://www.justice.gov/crt/fcs/T6Manual7 (last updated Feb. 10, 2017) (last accessed July 30, 2018).

 $^{^{21} \ \} For example, Alexander v. Sandoval, 532 \ U.S. \ 275 \ (2001) \ (holding that administrative agencies, but not private a support of the private of the private$ individuals, have the ability to enforce disparate impact nondiscrimination under Title VI).

²² Cummins & Isle, *supra* note 5 (detailing how the Reagan administration, the Federalist Society, and Republican judges sought to end disparate impact liability and how a number of cases—including Alexander v. Sandoval, 532 U.S. 275 (2001), Smith v. City of Jackson, 544 US 228 (2005), Ricci v. Stefano, 557 U.S. 557 (2009), Wal-Mart Stores, Inc. v. Dukes, 564 U.S. 338 (2011)—have 'dismantled' disparate impact in employment and beyond).

²³ See eg Susan Sturm, Equality and Inequality: Legal Aspects, in International Encyclopedia of Social and Behavioral Sciences 4717, 4717-22 (2001).

²⁴ Martha Albertson Fineman, Equality and Difference—the Restrained State, 66 Ala. L. Rev. 609, 610 (2015).

Erwin Chemerinsky, In Defense of Equality: A Reply to Professor Westen, 81 MICH. L. REV. 575, 599 (1983) (arguing equality is morally, analytically, and rhetorically necessary but itself insufficient to resolve legal controversies and explaining, at FN6, long-standing recognition that substantive values must inform which inequalities are intolerable).

²⁶ Roberts, supra note 6, at 629.

²⁷ For example, Balkin & Siegel, supra note 5; Siegel, supra note 5.

context.²⁸ Whereas a formal equality model adopts 'blindness' toward off-limits categories or forbidden classifications, a substantive equality model adopts a 'consciousness' of historical privilege, oppression, and vulnerabilities. The latter model would allow differential treatment that challenges or seeks to correct the historical oppression (including reasonable accommodations and diversity initiatives). Disparate impact liability is part of a substantive equality model, 'values merit, and questions only whether employers have too quickly seized on employment practices that assess merit only imperfectly, and at considerable cost to...equality of opportunity'.²⁹

While a formal equality model has dominated the law in the United States,³⁰ substantive equality and non-subordination principles have been considered the foundation of employment discrimination law (at least until relatively recently).³¹ It is within this broader context that GINA's disparate impact liability exclusion and departure from non-subordination principles must be viewed.

THE VAGUE LEGISLATIVE HISTORY FOR GINA'S DISPARATE IMPACT LIABILITY EXCLUSION

How the disparate impact liability exclusion became part of the legislation remains somewhat of a mystery. While there were five congressional hearings³² (see Table 1) held prior to the insertion of the provision that would limit employer liability for disparate impacts (see Table 2), there was no discussion on the record regarding whether neutral employment policies with discriminatory effects (ie disparate impacts) would be banned along with disparate treatment. Even during the two congressional hearings held after its insertion, ³³ the topic was not covered sufficiently on the record. ³⁴ In 2007 there were two brief remarks on the record signaling that business and trade lobbyists

- Illustrations are often useful in distinguishing these models. See eg the 'Equality Versus Equity' meme attributed to Lee Constable in Craig Froehle, The Evolution of an Accidental Meme, Medium, Apr. 14, 2016. https://medium.com/@CRA1G/the-evolution-of-an-accidental-meme-ddc4e139e0e4 (last accessed July 30, 2018).
- ²⁹ Rosenthal, *supra* note 5, at 2202.
- ³⁰ For example, Fineman, *supra* note 24; Kent Greenwalt, *How Empty is the Idea of Equality?*, 83 COLUM. L. REV. 1167 (1983); Donald J. Kochan, On Equality: the Anti-interference Principle, 45 U. RICH. L. REV. 431 (2011); Catherine A. MacKinnon, Substantive Equality: A Perspective, 96 MINN. L. REV. 1 (2011); Paul Stancil, Substantive Equality and Procedural Justice, 102 IOWA L. REV. 1633 (2017); R. George Wright, Equal Protection and the Idea of Equality, 34 LAW & INEQ. 1 (2016); Po-Jen Yap, Four Models of Equality, 27 LOY. L. A. INT'L & COMP. L. Rev. 63 (2015). See also Jennifer K. Wagner, DNA, Racial Disparities, and Biases in Criminal Justice: Searching for Solutions, 27 ALB. L. J. Sci. & Tech. 95, 118-23 (2017).
- 31 See Areheart, The Anticlassification, supra note 6; Areheart, GINA, Privacy, supra note 6.
- 32 Protection Against Genetic Discrimination: The Limits of Existing Laws, Hearing before the Comm. on Health, Education, Labor, and Pensions, 107th Cong. (2002); Fulfilling the Promise of Genetics Research: Ensuring Nondiscrimination in Health Insurance and Employment, Hearing before the Comm. on Health, Education, Labor, and Pensions, 107th Cong. (2001); Genetic Information in the Workplace, 106th Cong. (2000); Genetic Information and Health Care, Hearing before the Comm. on Labor and Human Resources, 105th Cong. (1998); and Advances in Genetics Research and Technologies: Challenges for Public Policy, Hearing before the Comm. on Labor and Human Resources, 104th Cong. (1996).
- Genetic Non-Discrimination: Examining the Implications for Workers and Employers, Hearing before the Subcomm. on Employer-Employee Relations, Committee on Education and the Workforce, 108th Cong. (2004) and Protecting Workers from Genetic Discrimination, Hearing Before the Subcomm. on Health, Employment, Labor and Pensions of the House Comm. on Education and Labor, 110th Cong. (2007).
- 34 The phrase 'disparate impact' only appears four times (three times in the record for the 2004 hearing and once in the 2007 hearing) and never with discussion directly on point. At no time was there discussion regarding the potential for disparate impact of a genetic underclass or group of individuals possessing a particular

Table 1. Relevant Congressional Hearings.

			-		
Congress	Date of Hearing	Senate Committee	Committee Chairman	Hearing Number	Hearing Title
104	7/25/1996	Labor and Human Resources	Nancy Landon Kassebaum (R-KS)	S. Hrg. 104–556	Advances in Genetics Research and Technologies: Challenges for Public Policy
105	5/21/1998	Labor and Human Resources	James M. Jeffords (R-VT)	S. Hrg. 105–580	Genetic Information and Health Care
106	7/20/2000	Health, Education, Labor, and Pensions		S. Hrg. 106–647	Genetic Information in the Workplace
107	7/21/2001	Health, Education, Labor, and Pensions	,	S. Hrg. 107–178	Fulfilling the Promise of Genetic Research: Ensuring Nondiscrimination in Health Insurance and Employment
107	2/13/2002	Health, Education, Labor, and Pensions	Edward M. Kennedy (D-MA)	S. Hrg. 107–286	Protecting Against Genetic Discrimination: The Limits of Existing Laws

(such as the U.S. Chamber of Commerce) were trying to narrow the bill's scope in any way possible and, as the bill moved closer to passage, the discussion homed in on ensuring that with this legislation Congress was targeting 'intentional and deliberate discrimination' rather than an 'accidental' violation.³⁵ The deliberations over GINA took place

genetic variant. Twice 'disparate impact' was mentioned merely to express support with the provision already contained within S.1053 to establish a commission, and twice 'disparate impact' was referenced to highlight the protections for genetic discrimination that might be possible under Title VII of the Civil Rights Act of 1964 if the employer's action or policy under scrutiny has created disparate impacts on the basis of race, sex, religion, and national origin once in the record for the two congressional hearings held after the provision appeared in the legislation. See *Genetic Non-Discrimination: Examining the Implications for Workers and Employers*, Hearing before the Subcomm. on Employer-Employee Relations, Committee on Education and the Workforce, 108th Cong. (2004) at 42 (statement of Lawrence Z. Lorber, Esq., Partner, Proskauer Rose LLP, on behalf of the U.S. Chamber of Commerce), at 47 (statement of the Genetic Information Nondiscrimination in Employment [GINE] Coalition) and at 79 (statement of the National Council on Disability) and see *Protecting Workers from Genetic Discrimination*, Hearing Before the Subcomm. on Health, Employment, Labor and Pensions of the House Comm. on Education and Labor, 110th Cong. (2007) at 52 (statement of Burton J. Fishman, Fortney & Scott, LLP, on behalf of the Genetic Information Nondiscrimination in Employment [GINE] Coalition).

³⁵ Protecting Workers from Genetic Discrimination, Hearing Before the Subcomm. on Health, Employment, Labor and Pensions of the House Comm. on Education and Labor, 110th Cong. (2007) at 18 (testimony of Rep.

Table 2. Legislative History of the Genetic Information Nondiscrimination Act of 2008 and Its Disparate Impact Provision.

Congress	Bill Congress Number	Name of Bill	Sponsor	Date Introduced	Number of Co-Sponsors	Vote (If Any)	Was Bill's Scope Health Insurance and Employment?	Did It Mention 'Disparate Impact'?
104	S.1694	Genetic Information Nondiscrimination in Health Insurance Act of 1995	Olympia Snowe (R-ME)	4/23/1995	1 (0 original)	n/a	No. Health insurance only	No.
104	S.1416	Genetic Privacy and Mark Ha Nondiscrimination Act of 1995 (R-OR)	Mark Hatfield (R-OR)	11/15/1995	Mark Hatfield 11/15/1995 2 (1 original) n/a (R-OR)	n/a	Yes.	No.
104	HR.2690	HR.2690 Genetic Privacy and Nondiscrimination Act of 1995		11/25/1995	Clifford Stearns $11/25/1995$ $35(0 \text{ original})$ n/a (R-FL)	n/a	Yes.	No.
104	HR.2748	HR.2748 Genetic Information Nondiscrimination in Health Insurance Act of 1995	Louise Slaughter (D-NY)	12/7/1995	76 (24 original) n/a	n/a	No. Health insurance only	No.
104	S.1600	Genetic Fairness Act of 1996	Dianne Feinstein (D-CA)	3/7/1996	1 (1 original)	n/a	No. Health insurance only	No.
104	S.1898	Genetic Confidentiality and Pete Dor Nondiscrimination Act of 1996 (R-NM)	Pete Domenici 6/24/1996 (R-NM)	6/24/1996	5 (0 original)	n/a	Yes.	No.
105	HR.306	Genetic Information Nondiscrimination in Health Insurance Act of 1997	Louise Slaughter (D-NY)	1/7/1997	213 (43 original)	n/a	No. Health insurance only	No.

Table 2. Continued

Congress Bill Nu	Bill Number	Name of Bill	Sponsor	Date Introduced	Number of Co-Sponsors	Vote (If Any)	Was Bill's Scope Health Insurance and Employment?	Did It Mention 'Disparate Impact'?
105	HR.328	Genetic Information Health Insurance Nondiscrimination Act of 1997	Gerald Solomon (R-NY)	1/7/1997	10 (0 original) n/a	n/a	No. Health insurance only	No.
105	HR.341	Genetic Privacy and Nondiscrimination Act of 1997	Clifford Stearns 1/7/1997 (R-FL)		9 (9 original)	n/a	Yes.	No.
105	8.89	Genetic Information Nondiscrimination in Health Insurance Act of 1997	Olympia Snowe (R-ME)	1/21/1997	26 (0 original) n/a	n/a	No. Health insurance only	o Z
105	S.422	Genetic Confidentiality and Nondiscrimination Act of 1997	Pete Domenici 3/11/1997 (R-NM)	3/11/1997	7 (2 original), excluding 1 withdrawn	n/a	Yes.	O Z
105	HR.2198	Genetic Privacy and Nondiscrimination Act of 1997 (R-FL)	Clifford Stearns 7/17/1997 (R-FL)		53 (37 original), excluding 1 withdrawn	n/a	Yes.	N o
105	HR.2215	HR.2215 Genetic nondiscrimination in the workplace act	Joseph Kennedy (D-MA)	7/22/1997	1 (0 original)	n/a	No. Employment No. only	o Z

Downloaded from https://academic.oup.com/jlb/article/5/3/527/5498594 by guest on 20 August 2022

Downloaded from https://academic.oup.com/jlb/article/5/3/527/5498594 by guest on 20 August 2022

Table 2. Continued

Congress Bill Nu	Bill Number	Name of Bill	Sponsor	Date Introduced	Number of Co-Sponsors	Vote (If Any)	Was Bill's Scope Health Insurance and Employment?	Did It Mention 'Disparate Impact'?
105	HR.2216	HR.2216 Genetic Protection in Insurance Joseph Coverage Act Kennec	Joseph Kennedy (D-MA)	7/22/1997	0	n/a	No. Life and disability insurance only	No.
105	S.1045	Genetic Justice Act	Thomas Daschle (D-SD)	7/22/1997	4 (0 original)	n/a	No. Employment only	No.
106	S.326	Patients' Bill of Rights Act	James Jeffords 1/28/1999 (R-VT)	1/28/1999	10 (8 original) n/a	n/a	No. Health insurance only	No.
106	S.543	Genetic Information Nondiscrimination in Health Insurance Act of 1999	Olympia Snowe (R-ME)	3/4/1999	7 (6 original)	n/a	No. Health insurance only	o V
106	HR.2457	HR.2457 Genetic Nondiscrimination in Health Insurance and Employment Act of 1999	Louise Slaughter (D-NY)	7/1/1999	164 (17 original)	n/a	Yes.	o V
106	S.1322	Genetic Nondiscrimination in Health Insurance and Employment Act of 1999	Thomas Daschle (D-SD)	7/1/1999	16 (3 original) n/a	n/a	Yes.	O

Table 2. Continued

Congress Bill Nu	Bill Number	Name of Bill	Sponsor	Date Introduced	Number of Co-Sponsors	Vote (If Any)	Was Bill's Scope Health Insurance and Employment?	Did It Mention 'Disparate Impact'?
107	8.19	Protecting Civil Rights for All Americans Act	Thomas Daschle (D-SD)	1/22/2001	27 (21 original) n/a	1/a	Yes.	%. *
107	HR.602	Genetic Nondiscrimination in Health Insurance and Employment Act	Louise Slaughter (D-NY)	2/13/2001	266 (151 original)	n/a	Yes.	o
107	S.318	Genetic Nondiscrimination in Health Insurance and Employment Act	Thomas Daschle (D-SD)	2/13/2001	29 (16 original) n/a	1/a	Yes.	No.
107	S.382	Genetic Information Nondiscrimination in Health Insurance Act of 2001	Olympia Snowe (R-ME)	2/15/2001	6 (5 original)	n/a	No. Health insurance only	o O
107	8.1995	Genetic Information Nondiscrimination Act of 2002	Olympia Snowe (R-ME)	3/6/2002	10 (7 original) n/a	1/a	Yes.	Yes.
108	8.16	Equal Rights and Equal Dignity Thomas for All Americans Act of 2003 Daschle (D-SD)	Thomas Daschle (D-SD)	1/7/2003	27 (21 original) n/a	1/a	Yes.	*. Z

Downloaded from https://academic.oup.com/jlb/article/5/3/527/5498594 by guest on 20 August 2022

Downloaded from https://academic.oup.com/jlb/article/5/3/527/5498594 by guest on 20 August 2022

Congress Bill Nu	Bill Number	Name of Bill	Sponsor	Date Introduced	Number of Co-Sponsors	Vote (If Any)	Was Bill's Scope Health Insurance and Employment?	Did It Mention 'Disparate Impact'?
108	HR.1910	HR.1910 Genetic Nondiscrimination in Health Insurance and Employment Act	Louise Slaughter (D-NY)	5/1/2003	242 (111 original)	n/a	Yes,	No.
108	S.1053	Genetic Information Nondiscrimination Act of 2003	Olympia Snowe (R-ME)	5/13/2003	23 (7 original) 95–0	95-0	Yes.	Yes.
108	HR.3636	HR.3636 Genetic Privacy and Clifford Nondiscrimination Act of 2003 (R-FL)	Clifford Stearns 11/21/2003 (R-FL)	11/21/2003	0	n/a	No. Health insurance only	No.
108	S.2083	Bipartisan Patient Protection Act of 2004	Barbara Boxer (D-CA)	2/12/2004	0	n/a	No. Health insurance only	No.
109	5.306	Genetic Information Nondiscrimination Act of 2005	Olympia Snowe (R-ME)	2/7/2005	25 (14 original) 98–0	0-86	Yes.	Yes.
109	HR.1227	Genetic Information Judy Bis Nondiscrimination Act of 2005 (R-IL)	Judy Biggert (R-IL)	3/10/2005	244 (37 original)	n/a	Yes.	Yes.
109	S.3822	Genomics and Personalized Medicine Act of 2006	Barack Obama (D-IL)	8/3/2006	0	n/a	Yes, as Sense of the No. Senate	No.

Table 2. Continued

Downloaded from https://academic.oup.com/jib/article/5/3/527/5498594 by guest on 20 August 2022

Table 2. Continued

Congress Bill Nun	Bill Number	Name of Bill	Sponsor	Date Introduced	Number of Co-Sponsors	Vote (If Any)	Vote (If Was Bill's Scope Did It Me Any) Health Insurance 'Disparat and Employment? Impact'?	Did It Mention 'Disparate Impact'?
109	HR.6125	HR.6125 Taxpayer Protection from Ron Pau Genetic Discrimination Act of (R-TX) 2006	1	9/20/2006 0	0	n/a	Yes.	No.
110	HR.493	Genetic Information Louise Nondiscrimination Act of 2008 Slaughter (D-NY)		1/16/2007	224 (143 original)	414–1 Yes.	Yes.	Yes.
110	S.358	Genetic Information Olympia Nondiscrimination Act of 2007 Snowe (R-ME)	_	1/22/2007	45 (22 original) 95-0		Yes.	Yes.

Over the 13 years that it took to pass genetic nondiscrimination legislation, there were at least 35 relevant bills introduced of varying scope and involving varying definitions. The deviation from other civil rights laws to exclude disparate impact liability for employers appeared for the first time in S.1995 introduced by Sen. Olympia Snowe in the 107th Congress. It did not appear in a House version until HR.1227 *The bill itself does, in a different section and different context not related to genetic nondiscrimination, mentions 'disparate impact'. introduced by Rep. Biggert in the 109th Congress.

Table 3. Political Party Control of Congress during GINA's Legislative History.

Congress	Contro	l of the U.S.	Senate*		l of the U.S. I	
	Rep	Dem	Other	Rep	Dem	Other
104 (1995–1997)	52	48	0	230	204	1
105 (1997–1999)	55	45	0	226	207	2
106 (1999–2001)	55	45	0	223	211	1
107 (2001–2003)***	49	50	1 (D)	220	213	2
108 (2003–2005)	51	48	1 (D)	229	205	1
109 (2005–2007)	55	45	1 (D)	233	201	1
110 (2007–2009)	49	49	2 (D)	202	233	0

 $^{^*}Data\ from\ U.S.\ Senate.\ 'Party\ Division'.\ https://www.senate.gov/history/partydiv.htm\ (last\ accessed\ Nov.\ 24,\ 2018).$

within the context of the broader debate—and bitter partisan division—over health care reform, with a Republican-controlled Congress blocking President Bill Clinton from achieving substantial health care reforms desired by Democrats. Republicans held control of the House of Representatives during the bulk of GINA's legislative history, having gained control in the 1994 mid-term elections and retaining that control until the 2006 mid-term elections. Republicans similarly held control of the Senate with exception of 2001–2002 following the move by Sen. James Jeffords (VT) to leave the Republican party to become an independent caucusing with the Democrats (see Table 3). The early genetic nondiscrimination bills never even made it to the floor for a vote while the Republicans controlled Congress. By the time the Democrats regained control of Congress with the 2006 mid-term elections, it is not surprising that they would strategically choose to advance the compromised bill that had already been endorsed by President George W. Bush rather than revisiting the text to remove this limitation on

^{**}Data from History, Art & Archives, U.S. House of Representatives. 'Party Divisions of the House of Representatives'. https://history.house.gov/Institution/Party-Divisions/Party-Divisions/(last accessed Nov. 24, 2018).

^{***}In the 107th Congress, control of the U.S. Senate shifted several times. Senate seats were evenly divided January 3, 2001 to January 20, 2001 with Vice President Al Gore having a tie-breaking vote giving the Democrats the majority. From January 20, 2001 to June 6, 2001, Vice President Richard Cheney held the tie-breaking vote giving the Republicans the majority. The numbers used in this table reflect the period of June 6, 2001 to November 12, 2002, as Senator James Jeffords left the Republican party and caucused with the Democrats as an Independent, thus giving control of the Senate to the Democrats.

Biggert in response to Mr. Kline's question,

And, Ms. Biggert, just to beat this horse one more time on this issue of intentional abuse versus accidental, I want to be clear that this language makes it clear that an employer who intentionally gets genetic information and intentionally discriminates against a potential or current employee because of that—that is what this legislation is aimed at, not accidental or unintentional misfiling kind of thing. Is that Correct?'

to which Rep. Biggert responded simply, 'That is correct'.) and at 46 (statement of Burton J. Fishman, Fortney & Scott, LLP, on behalf of the Genetic Information Nondiscrimination in Employment [GINE] Coalition, noting their support for a bill that 'is directed solely against intentional and deliberate discrimination').

liability and jeopardize the bipartisan support it had gained thus far or risk a potential presidential veto.

Committee reports³⁶ similarly lack detail regarding how the Committee on Health, Employment, Labor, and Pensions (HELP) arrived, after the 2002 hearing, at its compromise that led to the introduction of a unified bipartisan bill.³⁷ The compromise³⁸ made between the Republican³⁹ and Democratic⁴⁰ versions of the bill ultimately weakened the legislation by narrowing the employers who would be subject to the legislation's restrictions, removing the direct cause of action as an enforcement mechanism, and limiting the available remedies for a violation. The HELP Committee noted in 2003,

Due to the unique nature of genetic information and our current understanding of this developing area of science, the Committee has determined that only disparate treatment cases should be permitted under this legislation at this time.⁴¹

Yet it is unclear, and unstated, what led the Committee to this determination, as there is no documentation addressing why facially neutral policies with discriminatory effects on the basis of genetic information would be outside the reach of this law when it was expressly designed as a civil rights statute similar to Title VII, which allows liability for disparate impacts on the basis of race, color, religion, sex, or national origin unless the policy is job related and for a business necessity, ⁴² and the ADA, which allows for liability for disparate impacts on the basis of disability. ⁴³

When the Equal Employment Opportunity Commission (EEOC) announced its proposed rule for GINA's employment nondiscrimination provisions in 2009,⁴⁴ the agency reiterated the disparate impact liability exclusion in Section 1635.5: '... a cause of action for disparate impact within the meaning of section 703(k) of the Civil Rights Act of 1964, 42 U.S.C. 2000e-k(2), is not available under this part'. ⁴⁵ The EEOC further explained that the proposed rule did not address the study commission 'which is scheduled to begin its work on May 21, 2014'. ⁴⁶ While the EEOC expressly sought public comment that would go beyond the confines of the proposed rule, ⁴⁷ only three dozen (N = 36) written comments were submitted. ⁴⁸ Interestingly, only one comment—submitted by Jeffery Norris on behalf of the Equal Employment Advisory Council and the HR Policy Association—addressed disparate impact liability, having

³⁶ S. Rep. No. 108–122 (2003); S. Rep. 110–48 (2007).

³⁷ Genetic Information Nondiscrimination Act of 2003, S. 1053 (2003).

³⁸ Genetic Information Nondiscrimination Act of 2002, S. 1995 (2002).

³⁹ Genetic Information Nondiscrimination in Health Insurance Act of 2001, S.382, 107th Cong. (2001)

⁴⁰ Genetic Nondiscrimination in Health Insurance and Employment Act, S.318, 107th Cong. (2001)

⁴¹ S. Rep. No. 108–122, 29 (2003).

⁴² Supra note 7.

⁴³ Supra note 9 at § 12112(b)(3)(A).

Regulations Under the Genetic Information Nondiscrimination Act of 2008, 74 Fed. Reg. 9065 (proposed Mar. 2, 2009).

⁴⁵ *Id.* at 9068.

⁴⁶ Id. at 9060.

⁴⁷ *Id.* at 9057.

⁴⁸ See www.regulations.gov, search for Docket ID: EEOC-2009-0008 or RIN: 3046-AA84 and follow hyperlink to open docket folder (last accessed July 29, 2018). While the tally indicates 38 comments were received, review of all comments reveals that two were duplicate entries.

noted the organizations 'fully support' the proposed exclusion at Section 1635.5(b).⁴⁹ The Final Rule was issued by the EEOC six months later without change to the preamble discussion or relevant section.⁵⁰

Major news coverage is also unhelpful in clarifying the matter. Between the date the first genetic nondiscrimination bill was introduced (April 23, 1995) and the date GINA was signed into law (May 21, 2008), there were only 34 relevant articles in five major U.S. newspapers (the Chicago Tribune, Los Angeles Times, New York Times, Wall Street Journal, and Washington Post) (see Table 4). None of the articles mentioned 'disparate impact'. Only one of the articles even mentioned—albeit without specific explanation—why the Senate version of the bill with the disparate impact liability exclusion provision was pursued rather than the versions without that provision: Aaron Zitner reported,

Rep. Louise McIntosh Slaughter (D-N.Y.) said violators would face tougher penalties under a bill she filed in the House, which as 221 co-sponsors, including 44 Republicans. But Slaughter said she would urge House members to approve the Senate bill rather than her own to ease its passage into law.⁵¹

After reviewing the legislative history, it seems reasonable to conclude that the exclusion of disparate impact liability from the genetic nondiscrimination legislation was not a carefully deliberated decision based on actual congressional findings of fact or strong policy justifications. Rather, the feature was viewed as an improvement upon earlier versions because of (1) the ongoing challenges that legislators had in navigating the scientific concepts while drafting workable definitions for the legislation (such what 'genetic information' would be protected); (2) inflated, but frequently repeated, concerns voiced by legislation's opponents that potential conflicting regulatory obligations and inadvertent acquisitions of genetic information would open the floodgates to employer liability; ⁵² and (3) the desire to message this prophylactic legislation as both sufficiently narrow and urgently needed.

⁴⁹ See www.regulations.gov, search for Docket ID: EEOC-2009-0008 or RIN: 3046-AA84, follow hyperlink to open docket folder, and access comment with Tracking Number: 80971bce posted May 4, 2009 (last accessed July 29, 2018).

Regulations Under the Genetic Information Nondiscrimination Act of 2008, 75 Fed. Reg. 68912 (Final rule, Nov. 9, 2010), codified at 29 C.F.R. 1635.

Aaron Zitner, Senate Blocks Genetic Discrimination; Lawmakers Vote 95 to 0 to Prohibit Companies from Using Such Test Data in Job and Health Coverage Decisions, or in Assessing Premiums, Los Angeles Times, Oct. 15, 2003, at A16.

⁵² Protection Against Genetic Discrimination: The Limits of Existing Laws, Hearing before the Comm. on Health, Education, Labor, and Pensions, 107th Cong., 77–78 (2002) (statement of Ronald L. Adler, president, Laurden Associates, member of the Labor Relations Committee of the U.S. Chamber of Commerce). Mr. Adler's prepared statement noted,

As the President said in his radio address on this issue last June, any legislation seeking to protect against genetic discrimination must be 'fair, reasonable, and consistent with existing discrimination statutes.' From that perspective, I feel it is imperative that any proposed legislation in this area focus on prohibiting discriminatory conduct, rather than prohibiting the flow of information.

He elaborated to note the 'difficulty of regulating the flow of information between two individuals in the workplace" and warned of a "Pandora's box of regulatory nightmares' given how ADA, FMLA, and workers' compensation rules require extensive documentation of medical information that might, depending on how the legislation is drafted, create conflicting obligations for employers.

Table 4. Coverage of GINA's legislative history by Five Major U.S. News Outlets.

Date	News Outlet	Title	Author
3/3/1996	Los Angeles Times	The Dots Are Almost ConnectedThen What? Mapping the Human Genetic Code; They've almost cracked the human genetic code. That's the good news. What happens after that is the harder part	Laurie Garrett
4/12/1996	Washington Post	2 Marines face court-martial over DNA test; Case enters national debate on the use of genetic data	Bradley Graham
4/13/1996	New York Times	2 Marines who refused to comply with genetic-testing order face a court-martial	Neil A. Lewis
6/18/1996	New York Times	Trenton votes strict limits on use of gene tests by insurers	Jennifer Preston
4/27/1997	Los Angeles Times	Biotech: The Revolution Is Already Underway; Dolly the cloned sheep made headlines. But she is just one of many living inventions—created by the new world of biology—that are pushing the frontiers of science and society.	Robert Lee Hotz
7/20/1997	Chicago Tribune	Can laws protect us from our genes?	Cindy Schreuder
2/8/1998	Washington Post	Exposed: computer technology, managed health care and genetic science are all undermining the American tradition of medical privacy, in the name of progress. What can—or should—we do about it?	Arthur Allen
11/23/1999	Washington Post	Did freedom alone pay a nation's debt? Rep. John Conyers Jr. has a question. He's willing to wait a long time for the right answer.	Kevin Merida
2/9/2000	Los Angeles Times	Clinton Curbs use of genetic data; Privacy: Executive order limits federal agencies from gathering or using such information for personnel decisions. Experts call for comprehensive legislation	Alissa J. Rubin
5/23/2000	Washington Post	For DNA, a defining moment; with code revealed, challenge will be to find its meaning and uses series: The Human Blueprint: An Era Dawns	Rick Weiss
6/29/2000	New York Times	Excerpts from the President's news conference at the White House	n/a

Table 4. Continued

Date	News Outlet	Title	Author
1/1/2001	New York Times	New state laws tackle familiar national issues	Tamar Lewin
2/10/2001	New York Times	Commission sues railroad to end genetic testing in work injury cases	Tamar Lewin
2/21/2001	Wall Street Journal	Confidential! Genetics research is prompting calls for new privacy laws – before it's too late	Antonio Regalado
4/19/2001	Los Angeles Times	Railroad settles genetic testing case; workplace: Burlington Northern accepts order barring the worker exams in an important test case against the practice	Lisa Girion
6/24/2001	New York Times	Bush Supports federal law putting limits on DNA tests	David Sanger
6/24/2001	Chicago Tribune	Bush favors ban on gene-based discrimination. Abuse by insurers, employers feared	David Sanger
4/30/2002	Wall Street Journal	Genetics' Venter uses his profit for new causes	Scott Hensley
10/15/2003	Chicago Tribune	Senators vote to bar employer gene tests	Aaron Zitner
10/15/2003	Los Angeles Times	Senate Blocks Genetic Discrimination; Lawmakers vote 95 to 0 to prohibit companies from using such test data in job and health coverage decisions, or in assessing premiums.	Aaron Zitner
10/30/2003	Wall Street Journal	Breast-Cancer Genes Raise Questions	Mike Waldholz
2/6/2004	Wall Street Journal	Bill Seeking to Ban DNA Discrimination Isn't Really Necessary	Sharon Begley
3/7/2005	Los Angeles Times	Genes and financial fears	n/a
6/20/2005	Chicago Tribune	Genetics and Fear	n/a
10/15/2005	New York Times	The Knicks Have a Test Case in Medical Ethics	Liz Robbins

Table 4. Continued

Date	News Outlet	Title	Author
12/28/2005	Washington Post	Act now to prevent genetic discrimination	Susanne B. Haga and Huntington F. Willard
4/27/2007	Chicago Tribune	Genetic bill passes with ease, irony	Jim Tankersley
2/24/2008	New York Times	Fear of Insurance Trouble leads many to shun or hide DNA tests	Amy Harmon
4/23/2008	New York Times	Genetic-Discrimination Ban moves ahead in Congress	Andrew Pollack
4/24/2008	Washington Post	Ban on Genetic-Test Bias May Pass Senate	Rick Weiss
4/25/2008	Chicago Tribune	Senate: DNA bias not legal: House expected to pass ban on use of genetic profiles against workers	Judith Graham
4/25/2008	Los Angeles Times	Senate backs privacy for genetic data; The landmark bill would shield people from insurance and job discrimination based on test results	Ricardo Alonso- Zaldivar
5/2/2008	Los Angeles Times	Ban on genetic bias is passed by House	Jonathan D. Rockoff
5/2/2008	New York Times	Congress Passes Bill to Bar Bias Based On Genes	Amy Harmon

A search using Proquest U.S. Major Dailies newspaper database (which includes The New York Times, Washington Post, The Wall Street Journal, the Los Angeles Times, and the Chicago Tribune) with the search string DNA + discrimination + employment + bill was performed, and results were limited to those between April 23, 1995 (the date the first bill was introduced) and May 21, 2008 (the date GINA was signed into law). A manual review of the 50 total search results identified 34 relevant articles.

Interestingly, Senator Michael Enzi emphasized the importance of 'consistency' and stated that the bill 'must not deviate from other employment discrimination laws, namely, Title VII of the Civil Rights Act of 1964 and the Americans with Disabilities Act, with regard to enforcement and remedies'. 53 Yet the unified bipartisan bill that resulted did, in fact, conspicuously deviate by excluding disparate impact liability. While Senator Thomas Daschle argued '...a non-enforceable right is no right at all. Strong

⁵³ Protection Against Genetic Discrimination: The Limits of Existing Laws, Hearing before the Comm. on Health, Education, Labor, and Pensions, 107th Cong., 29 (2002) (statement of Senator Enzi). See also Cong. Rec. S1594 (2002).

remedies are the best way to ensure compliance...'54 and while the fervent opposition was mainly directed at (1) the proposed private cause of action in the health insurance discrimination provisions⁵⁵ and (2) the ability to seek judicial relief without exhausting administrative process first, disparate impact liability was nixed from the unified bill. The exclusion remained absent, however, from the House version until the 109th Congress.⁵⁶

When this legislative history is viewed within the broader context of employment discrimination law, it is hard to refute that GINA's disparate impact liability exclusion was the latest tactic used by Republicans in their protracted effort to pull the United States back from substantive equality and to dismantle disparate impact liability in employment (and other areas of) law. The Democrats' willingness to give up, at least temporarily, on disparate impact liability is aligned with the possibility that they saw gaining formal equality nondiscrimination protections for genetic information as better than nothing at all (ie GINA's protections were necessary but insufficient).

CONGRESS'S UNFINISHED BUSINESS

Regardless of how or why it arrived, the disparate impact liability exclusion became law when GINA was passed in 2008, as did the rest of Section 208 that contained the plans that Congress revisit whether disparate impact liability should be enabled after commission issued a report with recommendations. Notably, Section 208 was not drafted as optional. Rather, the plain language of Section 208 was such that the study commission's establishment was springing or, in other words, automatic (ie upon the sixth anniversary of GINA on May 21, 2014, the commission was established regardless of whether any members were appointed in advance);⁵⁷ the eight appointments of members were eight distinct statutory obligations, not merely permissions for the specified offices (as evinced by repetition of the words 'shall be appointed' when describing the authority of each office to appoint a member to the commission);⁵⁸ and the work product to be delivered was subject to a hard deadline so the commission could not continue or be at impasse indefinitely (as indicated by 'not later than 1 year after all of the members are appointed'). 59 These obligations, however, were perhaps illusory: who could lawfully or would politically hold those charged with the statutory obligation to appoint a member to the study commission accountable for failing to do so?⁶⁰

⁵⁴ Fulfilling the Promise of Genetics Research: Ensuring Nondiscrimination in Health Insurance and Employment, Hearing before the Comm. on Health, Education, Labor, and Pensions, 107th Cong., 9 (2001) (statement of Senator Daschle).

⁵⁵ During the congressional debates, it was repeatedly invoked that the Health Information Portability and Accountability Act of 1996 (HIPAA) did not permit a private cause of action (which Sen. Daschle's bill, S.318, would have allowed) and that enforcement for violations was solely via the Office of Civil Rights. See eg Fulfilling the Promise of Genetics Research: Ensuring Nondiscrimination in Health Insurance and Employment, Hearing before the Comm. on Health, Education, Labor, and Pensions, 107th Cong., 30 (2001) (statement of Kathleen Zeitz, Nebraska lead coordinator, National Breast Cancer Coalition).

 $^{^{56}\,\,}$ Genetic Information Nondiscrimination Act of 2005, H. R.1227 (2005).

⁵⁷ Section 208(b).

⁵⁸ Section 208(c)(1)(A)-(H).

⁵⁹ Section 208(e)

See eg U.S. Const. art. I, §5 (granting Congress the authority to govern itself). See also U.S. Congressional Research Service. Expulsion, Censure, Reprimand, and Fine: Legislative Discipline in the House of Representatives. (RL31382; Jun 27, 2016) by Jack Maskell; U.S. Congressional Research Service. Congress's Contempt

To date, there is no information readily available to indicate that any member of Congress enumerated in GINA as obligated to appoint a member to the commission has done so. Nor is there information readily available to indicate that the Genetic Nondiscrimination Study Commission has commenced work or delivered the requisite report. If complying with the letter of GINA, the appointments to the commission are now more than four years overdue. Unfortunately, GINA contains no citizen suit provision⁶¹ that would allow private citizens the ability to compel performance by the enumerated members of Congress (see Table 5) or, alternatively, the commission envisioned by Section 208.

DISPARATE IMPACT LIABILITY FOR GENETIC DISCRIMINATION IN EMPLOYMENT AND BEYOND

It is relevant, perhaps, to note that *non* discrimination is not necessarily synonymous with *anti* discrimination. One could argue that the former is passive (an observation of absence) and the other active (a counterbalancing force). In that sense, a *non* discrimination approach does not go as far as an *anti* discrimination approach would or should. GINA purports to be a forward-looking statute but does so in perhaps the most myopic way possible. Perhaps given the law's name involving *non* discrimination (rather than *anti* discrimination, fairness, or equality), it should not be a surprise that it deviates significantly from the employment discrimination statutes that preceded it (Title VII, ADA, and ADEA). As other scholars have observed, 4those preceding statutes were all focused on non-subordination (even if they have included anticlassification aspects) in that they allowed disparate impact liability, allowed affirmative action as remedial measures, and required reasonable accommodations. Looking at non-subordination and substantive equality is what 'tells us where GINA falls short."

Much of previous scholarship on GINA as a nondiscrimination law has centered on the fact that pre-GINA employment discrimination statutes were retrospective and trying to correct historical oppression of groups and that GINA is different, in part, because society has not recognized, stigmatized, marginalized, or oppressed 'a visible underclass'⁶⁶—or individuals have not yet developed obvious 'genetic identities' similar to our racial/ethnic, gender, and (dis)abled identities.⁶⁷ GINA's preemptive approach has been viewed as distinctive, and GINA's mandated privacy practices to

Power and the Enforcement of Congressional Subpoenas: Law, History, Practice, and Procedure. (RL34097; May 12, 2017) by Todd Garvey; Anant Rant & J. Benjamin Schrader, Dereliction of Duty: When Members of Congress Vote for Laws They Believe to be Unconstitutional, 10 N. Y. CITY L. REV. 511 (2007);

- 61 Citizen suit provisions are frequently included in environmental legislation to permit private citizens to compel performance on statutory obligations, including, eg, §509 Clean Water Act, 33 U.S.C. §1365.
- Whereas the prefix 'non' refers to 'not, lack of '(See Online Etymology Dictionary at www.etymonline.com; then search 'non-'), the prefix 'anti' refers to 'against, opposed to, opposite of, instead'. (See Online Etymology Dictionary at www.etymonline.com; then search 'anti-').
- 63 That is to say a non-critical perspective that ignores the possibility that there already are disparate impacts on the basis of genetic information pervasive throughout society, even if we do not regularly observe or articulate them as such.
- 64 For example, Areheart, GINA, Privacy, supra note 6, at 709. See also Areheart, The Anticlassification, supra note 6 (explaining that simplicity, popular support, and (ir) relevance of identity are three reasons why this turn to anti-classification principles has occurred).
- ⁶⁵ Supra note 26, at 648.
- ⁶⁶ Kim, *supra* note 6, at 698.
- ⁶⁷ Supra note 26, at 623–24.

Table 5. Elected Officials with the Obligation to Appoint One Member to the Genetic Nondiscrimination Study Commission Established by Statute on May 21, 2014.

	,	, ,
Congressional Office	Congress	Elected Official
Senate Majority Leader	113th	Harry Reid (D-NV)
	114th	Mitch McConnell (R-KY)
	115th	Mitch McConnell (R-KY)
Senate Minority Leader	113th	Mitch McConnell (R-KY)
	114th	Harry Reid (D-NV)
	115th	Charles Schumer (D-NY)
House Speaker	113th	John Boehner (R-OH)
	114th	Paul Ryan (R-WI)
	115th	Paul Ryan (R-WI)
House Minority Leader	113th	Nanci Pelosi (D-CA)
	114th	Nanci Pelosi (D-CA)
	115th	Nanci Pelosi (D-CA)
Senate HELP Committee Chair	113th	Tom Harkin (D-IA)
	114th	Lamar Alexander (R-TN)
	115th	Lamar Alexander (R-TN)
Senate HELP Committee Ranking Member	113th	Lamar Alexander (R-TN)
	114th	Patty Muray (D-WA)
	115th	Patty Muray (D-WA)
House Committee on Education and Labor	113th	John Kline (R-MN)
(Later renamed the Committee on Education and the Workforce) Chair	114th	John Kline (R-MN)
and the Worklotee) chair	115th	Virginia Foxx (R-NC)
House Committee on Education and Labor	113th	George Miller (D-CA)
(Later renamed the Committee on Education and the Workforce) Ranking Member	114th	Robert C. Scott (D-CA)
	115th	Robert C. Scott (D-CA)

As per Section 208(c) of GINA, each of the offices listed below (regardless of the individual who held that office) was to appoint one member to the study commission.

promote nondiscrimination have been viewed by some as a means to benefit everyone, regardless of any 'genetic identities'.68

Preventing the 'insidious creation of a genetic underclass that is denied participation in the liberal economy'69 requires us to go beyond genomic sequence data, beyond disparate treatment liability, and beyond the employment context. GINA establishes an indefinite number of protected classes and asserts that use of genetic information is always an unfair basis upon which to make employment decisions intentionally. By not enabling disparate impact liability, however, victims only have legal remedy if they can demonstrate the employer's use of pretext or mixed motives⁷⁰ and countless genetic underclasses could persist or expand. Moreover, GINA was already severely limited in scope by not anticipating and staving off numerous potential genetic underclasses in education, housing, lending, commerce, federally funded or run programs, and other opportunities.

Since GINA's passage in 2008, genetic science and technologies have developed and expanded, and the number of individuals having their genomes analysed—whether clinically, as part of participation in research, or through direct-toconsumer options—has increased dramatically. The personal genomics industry continues to grow, and gaining access to genomic information is becoming easier for individuals in the United States.⁷¹ However, public awareness of GINA remains low, and there has been relatively little GINA litigation. 72 While the Affordable Care Act has rendered GINA Title I protections moot by expanding health insurance nondiscrimination rights, 73 GINA Title II remains valuable legislation to protect individuals' genetic privacy and nondiscrimination rights in the workplace.⁷⁴ It is important for legislation to keep up with the pace of the technology, meet the emerging challenges, and close gaps in legal nondiscrimination protections once discovered.

Congress has unfinished business, and scholars in relevant fields (including but not limited to genetics, bioinformatics, anthropology, sociology, biomedical science, etc.) must conduct empirical and normative research that could inform the policy work not yet completed. After 10 years of GINA and countless developments in genomics and informatics, it is time to revisit disparate impact liability and to do so with a progressive eye not only toward genetic information but also other 'big data'. The Genetic Nondiscrimination Study Commission should be empaneled and commence work to issue a report as soon as possible. Among the many issues the commission and Congress

See Roberts, supra note 6; Travis, supra note 5, at 560, 567.

Ajunwa, supra note 6, at 114.

⁷⁰ See eg *supra* note 13 and Price Waterhouse v. Hopkins, 490 U.S. 228 (1989).

⁷¹ See The National Academies of Sciences, Engineering, and Medicine, 'Returning individual research results to participants: Guidance for a new research paradigm' (Consensus Study Report, 2018), https://www.nap.edu/catalog/25094/returning-individual-research-results-to-participants-guidance-for-a-results-to-participants-guidance-for-a-results-to-participants-guidance-for-a-results-to-participants-guidance-for-a-results-to-participants-guidance-for-a-results-to-participants-guidance-for-a-results-to-participants-guidance-for-a-results-to-participants-guidance-for-a-results-to-participants-guidance-for-a-results-to-participants-guidance-for-a-results-to-participants-guidance-for-a-results-to-participants-guidance-for-a-results-to-participants-guidance-for-a-results-to-participants-guidance-for-a-results-to-participants-guidance-for-a-results-to-participants-guidance-for-a-results-to-participants-guidance-for-a-results-to-participants-guidance-for-a-results-guidanew (last accessed Feb. 12, 2019); Susan M. Wolf & Barbara J. Evans, Return of Results and Data to Study Participants, 362 SCIENCE 159 (2018); Jeffrey R. Botkin et al., Standardizing Return of Participant Results, 362 SCIENCE 759 (2018).

 $^{^{72}~}$ See Bradley A. Areheart & Jessica L. Roberts, The Future of Genetic Privacy, 128 Yale L. J. 710 (2019)

⁷³ Patient Protection and Affordable Care Act, Pub. L. No. 111-148, 124 Stat. 119-1025 (2010).

 $^{^{74}}$ There have been unsuccessful attempts to weaken GINA's protections, most notably involving the rule making to reconcile inconsistencies between GINA and the ACA with regard to voluntary wellness programs. See 80 Fed. Reg. 66853 (2015); 81 Fed. Reg. 31143 (2016); AARP v. EEOC, 292 F. Supp. 3d 238 (2017); and Preserving Employee Wellness Programs Act, H. R. 1313 (2017).

should consider is that fairness and equality in the future will require a more progressive vision than passive approaches that prohibit only overt discrimination. With genetics, statistical discrimination is a substantial problem: linkage disequilibrium means that many (of not most) 'neutral' policies based on manifested traits and conditions that could themselves be job-related would create one or more genetic underclasses that we as a society would not want to create. One way to promote substantive equality would be for Congress to incentivize the documentation of antidiscrimination measures⁷⁵ taken by employers to ensure that not only are practices and policies free from overt, intentional genetic discrimination but also proactively designed to minimize discriminatory effects. Another topic ripe for study by the commission is whether and how an employer's failure to prevent disparate impacts might give rise to an inference of disparate treatment. 76 With advances in big data and informatics, it is increasingly difficult to rely on categories as 'protected classes', because the increased granularity with which data can be segmented enables extensive discrimination on levels that would evade identification as a visible underclass. If disparate impact liability is not available and a return to non-subordination principles is not taken to promote equality, it will be increasingly difficult to enforce the current civil rights laws, including but not limited to GINA. A disparate impact claim would be one in which a neutral employment policy (ie a policy that is not explicitly based on genetic information) nevertheless has disproportionate effects on groups of individuals based on genetic information. This could potentially be the most important type of nondiscrimination protections for individuals who, despite not expressing a trait or being symptomatic, have heightened genetic risks for conditions with incomplete penetrance and variable expressivity. This also could potentially be the most important type of genetic nondiscrimination protection when one views genetics through an omnigenic model of phenotypic variation.⁷⁷ Policymakers will increasingly need assistance from the scientific community to understand where an appropriate line is to be drawn between fair and unfair genetic discrimination.

ACKNOWLEDGEMENTS

This work was funded in part by grant no. 5R00HG006446-05 from the National Human Genome Research Institute (NHGRI). The content of this article is the author's responsibility and might not represent the official views of the author's funding sources, employers, clients, or any other person or entity. The author has no financial, personal, academic, or other conflicts of interest in the subject matter discussed in this manuscript. The author thanks Anya Prince, Jessica Roberts, and Derek Scholes for encouragement during the preparation of this manuscript.

See eg Bettina Berendt & Sören Preibusch, Toward Accountable Discrimination-Aware Data Mining: The Importance of Keeping the Human in the Loop—and Under the Looking Glass, 5 Big Data 135 (2017); Brian d'Alessandro, Cathy O'Neil, & Tom LaGatta, Conscientious Classification: A Data Scientist's Guide to Discrimination Aware Classification, 5 BIG DATA 120 (2017).

 $^{^{76}}$ See eg Bornstein, supra note 5 (suggesting tort theories of causation would be useful in disparate treatment cases of employment discrimination).

⁷⁷ Evan A. Boyle, Yang I. Li, & Jonathan K. Prichard, An Expanded View of Complex Traits: From Polygenic to Omnigenic, 169 CELL 1177 (2017). See also Ed Yong, What If (Almost) Every Gene Affects (Almost) Everything?, THE ATLANTIC (2017), https://www.theatlantic.com/science/archive/2017/06/its-like-allconnected-man/530532/ (last accessed Dec. 2, 2018).