

# Big Data and the Americans with Disabilities Act

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*While big data offers society many potential benefits, it also comes with serious risks. This Article focuses on the concern that big data will lead to increased employment discrimination. It develops the novel argument that the Americans with Disabilities Act (“ADA”) should be amended in response to the proliferation of big data in order to protect individuals who might be categorized as likely to develop physical or mental impairments in the future.*

*Employers can obtain medical data about employees not only through the traditional means of medical examinations and inquiries, but also through the nontraditional mechanisms of social media, wellness programs, and data brokers. Information about workers’ habits, behaviors, or attributes that is derived from big data can be used to create profiles of undesirable employees. It can also be used to exclude healthy and qualified individuals whom employers regard as vulnerable to future medical problems. The ADA, which now protects only individuals with current or past disabilities and those who are perceived as having existing impairments, can no longer ignore the discrimination threats posed by predictive health data. This Article analyzes these risks and proposes a detailed statutory response to them.*

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## TABLE OF CONTENTS

INTRODUCTION.....	778
I. EMPLOYERS AND BIG DATA .....	780
A. HOW EMPLOYERS OBTAIN INDIVIDUALS’ HEALTH INFORMATION.....	780
1. <i>Traditional Sources—Medical Examinations             and Inquiries</i> .....	780
2. <i>Social Media</i> .....	780
3. <i>Wellness Programs</i> .....	781
4. <i>Data Brokers</i> .....	782
5. <i>Data De-Identification</i> .....	783
B. DISEASE PREDICTION AND THE RISK OF EMPLOYMENT DISCRIMINATION .....	784
II. THE AMERICANS WITH DISABILITIES ACT.....	786
III. RECOMMENDED ADA REVISIONS.....	787
A. EXPANDING THE “REGARDED AS” PROVISION.....	787
1. <i>Overlap with GINA</i> .....	788
2. <i>Exceptions for Risk-Taking Behaviors</i> .....	789
3. <i>Obesity</i> .....	790
B. DISCLOSING DATA MINING PRACTICES .....	791
CONCLUSION .....	792

## INTRODUCTION

Big data has generated great enthusiasm among academics, policymakers, corporate analysts, and many others.<sup>1</sup> Indeed, big data use may well lead to important scientific discoveries, more effective quality assessment initiatives, public health policy improvements, cost savings, new patient support tools, and much more.<sup>2</sup> But big data can also fall into the hands of those who do not have the data subjects’ best interest in mind.<sup>3</sup> Employers, financial institutions, marketers, and others with financial agendas can use big data to make adverse decisions that deprive individuals of various opportunities or take advantage of their

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1. Sharona Hoffman, *Medical Big Data and Big Data Quality Problems*, 21 CONN. INS. L.J. 289, 289 (2014).

2. Sharona Hoffman & Andy Podgurski, *The Use and Misuse of Biomedical Data: Is Bigger Really Better?*, 39 AM. J.L. & MED. 497, 506–15 (2013).

3. EXEC. OFFICE OF THE PRESIDENT, BIG DATA: SEIZING OPPORTUNITIES, PRESERVING VALUES 51–53 (2014).

vulnerabilities.<sup>4</sup> For example, based on big data analysis, an individual may not receive a job offer, loan, or investment opportunity.<sup>5</sup>

Employers are particularly likely to be interested in health information about applicants and employees because they desire productive workers in order to be profitable. Moreover, since the majority of Americans obtain health insurance through employers,<sup>6</sup> those employers also have an incentive to exclude employees who will generate high health insurance costs. Thus, they may be very motivated to obtain information indicating whether particular individuals currently have health problems or are likely to develop them in the future.

This Article asks whether the Americans with Disabilities Act (“ADA”)<sup>7</sup> provides sufficient antidiscrimination protections to workers in the era of big data. The answer is no. The ADA protects only individuals who are currently disabled, have records of past disabilities, or are regarded as having existing impairments.<sup>8</sup> As such, it does not reach far enough. It does not stretch to cover individuals who are perfectly healthy at present but whom an employer suspects of being at risk of serious ailments later in life based on big data analysis.

This Article offers a two-fold approach to addressing discrimination based on predictions of future health problems.<sup>9</sup> First, the ADA must be amended to prohibit discrimination based on an employer’s belief that an individual is likely to develop a physical or mental impairment in the future. Second, the law must require employers to disclose in writing to applicants and employees any practices other than medical exams and direct medical inquiries by which they seek health-related information, including predictive data.

A point-of-use solution is a more realistic and effective means to combat discrimination than a blanket prohibition on big data use, which would likely be unenforceable. Thus, a well-tailored and promising means to address concerns about big data is to prohibit their use for discriminatory purposes.

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4. Sharona Hoffman, *Citizen Science: The Law and Ethics of Public Access to Medical Big Data*, 30 BERKELEY TECH. L.J. 1741, 1772–80 (2015).

5. *Id.* at 1772–76.

6. *Number of Americans Obtaining Health Insurance Through an Employer Declines Steadily Since 2000*, ROBERT WOOD JOHNSON FOUND. (Apr. 11, 2013), <http://www.rwjf.org/en/library/articles-and-news/2013/04/number-of-americans-obtaining-health-insurance-through-an-employ.html> (finding that 59.5% of Americans in 2011 obtained health insurance through employers).

7. Americans with Disabilities Act, 42 U.S.C. §§ 12101–12213 (2010).

8. *Id.* § 12102 (defining the term “disability”).

9. *See infra* Part III.

## I. EMPLOYERS AND BIG DATA

Employers can learn a great deal about their applicants and employees from big data. This Part explores how employers obtain big data and what that data can tell them.

### A. HOW EMPLOYERS OBTAIN INDIVIDUALS' HEALTH INFORMATION

The contemporary, high-tech, data-driven world offers employers a vast array of information sources about workers. These range from ordinary medical examinations to social media, wellness programs, and data brokers.

#### 1. *Traditional Sources—Medical Examinations and Inquiries*

Employers routinely gain medical information about applicants and employees through medical examinations and inquiries.<sup>10</sup> The ADA allows them to do so, with limited restrictions, in order to judge whether individuals are qualified for particular jobs or can continue to perform them safely.<sup>11</sup> Many employers require workers to sign forms authorizing physicians to send them copies of the patient's entire health record upon request.<sup>12</sup> According to Professor Mark Rothstein, each year there are twenty-five million compelled authorizations in the United States.<sup>13</sup> Thus, employers are able to obtain a wealth of information about workers by submitting simple record requests to their doctors.

#### 2. *Social Media*

Enterprising employers may also turn to less conventional sources to gain information about their applicants and employees. Because the ADA, a law enacted in 1990,<sup>14</sup> contemplates only traditional medical

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10. Sharona Hoffman, *Employing E-Health: The Impact of Electronic Health Records on the Workplace*, 19 KAN. J.L. & PUB. POL'Y 409, 409–10 (2010).

11. 42 U.S.C. § 12112(d). In general, employers are not permitted to conduct medical examinations or make medical inquiries during the application process, though they may examine applicants' ability to perform job-related tasks. After extending bona fide offers of employment, but before the commencement of employment, employers may conduct medical examinations so long as all entering employees undergo them, employers maintain confidentiality regarding results, and the information is not used for purposes of unlawful discrimination. After the commencement of employment, any medical exam or inquiry must be job-related. *Id.*; Sharona Hoffman, *Preplacement Examinations and Job-Relatedness: How to Enhance Privacy and Diminish Discrimination in the Workplace*, 49 U. KAN. L. REV. 517, 523–26 (2001).

12. Mark A. Rothstein, *GINA, the ADA, and Genetic Discrimination in Employment*, 36 J.L. MED. & ETHICS 837, 838 (2008).

13. Mark A. Rothstein, *Access to Sensitive Information in Segmented Electronic Health Records*, 40 J.L. MED. & ETHICS 394, 397 (2012).

14. *The Americans with Disabilities Act of 1990*, U.S. EQUAL EMP. OPPORTUNITY COMMISSION, <https://www.eeoc.gov/eeoc/history/35th/1990s/ada.html> (last visited Apr. 23, 2017).

exams or questions that are posed directly to workers or their physicians, it does not address or restrict other means of obtaining health data.<sup>15</sup>

Employers can and do scour Facebook, Twitter, and other social media platforms in which workers reveal abundant details about themselves.<sup>16</sup> Moreover, employers are known to base employment decisions on information that they find on such sites. For example, in a 2016 case, a district court granted summary judgment to an employer that fired an employee for abusing his medical leave following shoulder surgery.<sup>17</sup> The employer discovered photos on Facebook from several vacation trips that the employee took while on leave and concluded that the individual did not actually require time away from work for health reasons.<sup>18</sup> The employee sued for violation of the Family Medical Leave Act, but the court ruled against him.<sup>19</sup> It is not inconceivable that employers will look not only for evidence of worker misconduct, but also for information about individuals' habits, behaviors, or traits that could be predictive of future health problems.

### 3. *Wellness Programs*

Many employers have instituted wellness programs in order to try to improve employees' health and thereby save healthcare costs.<sup>20</sup> According to the Kaiser Family Foundation, in 2016, eighty-three percent of firms with 200 or more workers that offered health benefits had some type of wellness program.<sup>21</sup> Fifty-nine percent of these programs included health risk assessments, and fifty-three percent included biometric screening.<sup>22</sup>

Therefore, wellness program participants often disclose details about their health to wellness vendors. These vendors, in turn, may share aggregated information about the workforce with employers.<sup>23</sup> Smaller

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15. 42 U.S.C. § 12112(d).

16. Steven L. Thomas et al., *Social Networking, Management Responsibilities, and Employee Rights: The Evolving Role of Social Networking in Employment Decisions*, 27 EMP. RESP. & RTS. J. 307, 307 (2015); Janet Ford et al., *New Concerns in Electronic Employee Monitoring: Have You Checked Your Policies Lately?*, 18 J. LEGAL ETHICAL & REG. ISSUES 51, 51 (2015).

17. *Jones v. Gulf Coast Health Care of Del., LLC*, No. 8:15-CV-702-T-24EAJ, 2016 WL 659308, \*1 (M.D. Fla. Feb. 18, 2016), *appeal filed*, *Jones v. Gulf Coast Health Care of Del., LLC*, No. 16-11142 (11th Cir. Mar. 15, 2016).

18. *Id.* at \*2.

19. *Id.* at \*5.

20. Reed Abelson, *Employee Wellness Programs Use Carrots and, Increasingly, Sticks*, N.Y. TIMES (Jan. 24, 2016), [http://www.nytimes.com/2016/01/25/business/employee-wellness-programs-use-carrots-and-increasingly-sticks.html?\\_r=0](http://www.nytimes.com/2016/01/25/business/employee-wellness-programs-use-carrots-and-increasingly-sticks.html?_r=0).

21. 2016 EMPLOYER HEALTH BENEFITS SURVEY, KAISER FAM. FOUND. (2016), <http://kff.org/report-section/chbs-2016-summary-of-findings/>.

22. *Id.*

23. Jay Hancock, *Workplace Wellness Programs Put Employee Privacy at Risk*, CNN (last updated Oct. 2, 2015, 12:37 PM), <http://www.cnn.com/2015/09/28/health/workplace-wellness-privacy-risk-exclusive/>; Rachel Emma Silverman, *Bosses Tap Outside Firms to Predict Which Workers Might Get Sick*, WALL ST. J.

employers may not use vendors, but rather run wellness programs themselves and obtain certain health information directly from employees.<sup>24</sup> The ADA explicitly permits employers to “conduct voluntary medical examinations, including voluntary medical histories, which are part of an employee health program available to employees at that work site.”<sup>25</sup>

Some employers provide their employees with Fitbits that collect data about individuals’ exercise patterns, calorie intake, sleep habits, weight, and more.<sup>26</sup> Fitbit also sells analytics platforms to employers that they can use to negotiate group rates with health insurers or to create incentive programs that encourage employees to engage in healthy habits.<sup>27</sup> Some speculate that employers may obtain not only de-identified summary data but also individualized information about their workers from Fitbits and wellness vendors.<sup>28</sup> It is noteworthy that these products and vendors are not subject to the confidentiality mandates of the Health Insurance Portability and Accountability Act (“HIPAA”) Privacy Rule.<sup>29</sup>

#### 4. Data Brokers

Numerous data brokers collect personal information from a variety of public and private sources and create personal profiles of individuals that they market to any interested party.<sup>30</sup> Data brokers sell lists of individuals with sexually transmitted diseases, Alzheimer’s, dementia, AIDS, depression, and other ailments.<sup>31</sup> Data brokers mine sources such as social media, personal websites, U.S. Census records, retailers’

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(last updated Feb. 17, 2016, 7:58 PM), <http://www.wsj.com/articles/bosses-harness-big-data-to-predict-which-workers-might-get-sick-1455664940>.

24. *How to Set up a Wellness Plan*, WALL ST. J. (Sept. 12, 2008, 2:25 PM), <http://guides.wsj.com/small-business/hiring-and-managing-employees/how-to-set-up-a-wellness-plan/tab/print/>.

25. Americans with Disabilities Act, 42 U.S.C. § 12112(d)(4)(B) (2010); see *EEOC’s Final Rule on Employer Wellness Programs and Title I of the Americans with Disabilities Act*, U.S. EQUAL EMP. OPPORTUNITY COMMISSION, <https://www.eeoc.gov/laws/regulations/qanda-ada-wellness-final-rule.cfm> (last visited Apr. 23, 2017).

26. Farai Chideya, *Medical Privacy Under Threat in the Age of Big Data*, THE INTERCEPT (Aug. 6, 2015, 9:42 AM), <https://theintercept.com/2015/08/06/how-medical-privacy-laws-leave-patient-data-exposed/>.

27. *Id.*

28. Sarah Kellogg, *Every Breath You Take: Data Privacy and Your Wearable Fitness Device*, 30 WASH. LAW. 22, 28 (2015); Jay Hancock, *Is Your Private Health Data Safe in Your Workplace Wellness Program?*, PBS NEWSHOUR (Sept. 30, 2015, 6:07 PM), <http://www.pbs.org/newshour/updates/many-workplace-wellness-programs-dont-follow-health-privacy-laws/>.

29. 45 C.F.R. §§ 160.102–160.103 (2015); 42 U.S.C. § 17934. The HIPAA Privacy Rule covers only health plans, healthcare clearinghouses, healthcare providers who transmit health information electronically for purposes of HIPAA-relevant transactions, and their business associates. *Id.*

30. *Spokeo to Pay \$800,000 to Settle FTC Charges Company Allegedly Marketed Information to Employers and Recruiters in Violation of FCRA*, FED. TRADE COMMISSION (June 12, 2012), <https://www.ftc.gov/news-events/press-releases/2012/06/spokeo-pay-800000-settle-ftc-charges-company-allegedly-marketed>; Kellogg, *supra* note 28, at 27.

31. Frank Pasquale, Opinion, *The Dark Market for Personal Data*, N.Y. TIMES (Oct. 16, 2014), [http://www.nytimes.com/2014/10/17/opinion/the-dark-market-for-personal-data.html?\\_r=0](http://www.nytimes.com/2014/10/17/opinion/the-dark-market-for-personal-data.html?_r=0).

purchasing records, real property records, insurance claims, and more.<sup>32</sup> By some estimates, several thousand data brokers already exist,<sup>33</sup> including well-known vendors such as Spokeo and Axiom.<sup>34</sup>

Some data brokers sell specific services to employers. Walmart reportedly hired a company called Castlight to identify workers with back problems who were filing insurance claims so that they could be sent information that would discourage them from having surgery, such as recommendations for physical therapy and for obtaining second opinions.<sup>35</sup> Likewise, Walmart reportedly asked Castlight to identify women who stopped filling birth control prescriptions and to determine, based on their ages and the ages of their other children, whether they likely stopped doing so because they are planning to become pregnant.<sup>36</sup> The data were then purportedly used to send them tips for choosing an obstetrician and pursuing prenatal care.<sup>37</sup>

As employers become more familiar and comfortable with data brokers, they may more frequently seek information about their applicants and employees from these data providers, including details relating to health risks. While some may do so in order to help workers improve their health, others may base discriminatory decisions upon this information.

### 5. *Data De-Identification*

The data that employers obtain from data brokers or wellness programs will often be de-identified.<sup>38</sup> It is important to understand, however, that de-identification does not fully protect data subjects because de-identified information can sometimes be re-identified by skilled experts. Data miners can match information to publicly available data, such as voter registration records, media stories about accidents and illnesses, and other sources in order to re-identify anonymized records.<sup>39</sup> For example, in 1997, Latanya Sweeney, now a Harvard professor, was able to identify Governor William Weld's hospital records after spending twenty dollars to purchase anonymized state employee

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32. Gary Anthes, *Data Brokers Are Watching You*, 58 COMM. ACM 28, 28–30 (2015).

33. Pasquale, *supra* note 31 (“The World Privacy Forum, a research and advocacy organization, estimates that there are about 4,000 data brokers.”); Paul Boutin, *The Secretive World of Selling Data About You*, NEWSWEEK (May 30, 2016, 2:30 PM), <http://www.newsweek.com/secretive-world-selling-data-about-you-464789> (“Credible estimates range from 2,500 to 4,000.”).

34. SPOKEO, [http://www.spokeo.com/?g=name\\_gs\\_C000213&gclid=CK617oWG-oCFYsAaQod2moCkQ](http://www.spokeo.com/?g=name_gs_C000213&gclid=CK617oWG-oCFYsAaQod2moCkQ) (last visited Apr. 23, 2017); ACXION, <http://www.acxiom.com/> (last visited Apr. 23, 2017).

35. Silverman, *supra* note 23.

36. *Id.*

37. *Id.*; Aimee Picchi, *The “Big Data” App That Predicts Employees’ Health*, CBS NEWS (Feb. 18, 2016, 1:56 PM), <http://www.cbsnews.com/news/the-big-data-app-that-predicts-employees-health/>.

38. Hancock, *supra* note 28.

39. Sharona Hoffman & Andy Podgurski, *Balancing Privacy, Autonomy, and Scientific Needs in Electronic Health Records Research*, 65 SMU L. REV. 85, 105–07 (2012).

hospital records and matching them to voter registration records for the city of Cambridge, Massachusetts.<sup>40</sup> In fact, no matter how carefully data is de-identified, the risk of re-identification can never be fully eliminated.<sup>41</sup> It will be no surprise if enterprising employers retain experts to re-identify anonymized information in order to enhance the data they have for purposes of employment decisions.

Yet, even de-identified data can be useful to employers. Such data might enable them to learn a great deal about disease risks and trends and to develop profiles of undesirable employees. For instance, the Centers for Disease Control and Prevention's ("CDC") website, CDC Wonder, allows users to search for cancer incidence by age, sex, race, ethnicity, and region.<sup>42</sup> Employers (or their agents) could thus conduct data searches to determine whether certain demographics or other attributes are closely associated with particular diseases.<sup>43</sup> To illustrate, if employers discover that some cancers are most common among women over fifty of a specific ethnicity, they may decide that such women are unappealing job candidates.

#### B. DISEASE PREDICTION AND THE RISK OF EMPLOYMENT DISCRIMINATION

Traditionally, diseases could be detected and diagnosed only once symptoms became apparent. Increasingly, however, medical experts can determine that certain behaviors or traits render individuals vulnerable to future ailments.<sup>44</sup> Obvious examples are smoking (which is associated with risks of various cancers, heart disease, stroke, and other serious conditions) and alcoholism (which is associated with impairments of the heart, liver, pancreas, and other systems).<sup>45</sup> In addition, women who have

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40. Paul Ohm, *Broken Promises of Privacy: Responding to the Surprising Failure of Anonymization*, 57 UCLA L. REV. 1701, 1719–20 (2010); Kathleen Benitez & Bradley Malin, Research Paper, *Evaluating Re-Identification Risks with Respect to the HIPAA Privacy Rule*, 17 J. AM. MED. INFORMATICS ASS'N 169, 169 (2010); Latanya Sweeney, *Only You, Your Doctor, and Many Others May Know*, TECH. SCI. (Sept. 29, 2015), <http://techscience.org/a/2015092903/>. The hospital records did not contain obvious identifiers such as name and street address, but they did contain the patients' birthdates, sexes, and zip codes. Re-identification was possible because only six people in Cambridge shared Governor Weld's birth date and only three were men. Among the men, only he lived in his zip code. See Sweeney, *supra*.

41. Hoffman & Podgurski, *supra* note 39, at 105–07.

42. *United States Cancer Statistics, 1999–2010 Incidence Archive Request*, CTRS. FOR DISEASE CONTROL & PREVENTION, <http://wonder.cdc.gov/cancer-v2010.html> (last visited Apr. 23, 2017).

43. See Hoffman, *supra* note 4, at 1776–78.

44. Francie Diep, *How to Predict a Lifetime of Diseases*, POPULAR SCI. (June 24, 2014), <http://www.popsci.com/article/science/how-predict-lifetime-diseases>.

45. *What Are the Risks of Smoking?*, NAT'L. HEART, LUNG, & BLOOD INST., <https://www.nhlbi.nih.gov/health/health-topics/topics/smo/risks> (last visited Apr. 23, 2017); *Harms of Cigarette Smoking and Health Benefits of Quitting*, NAT'L. CANCER INST. (last reviewed Dec. 3, 2014), <http://www.cancer.gov/about-cancer/causes-prevention/risk/tobacco/cessation-fact-sheet>; *Alcohol's Effects on the Body*, NAT'L. INST. ON ALCOHOL ABUSE & ALCOHOLISM, <http://www.niaaa.nih.gov/alcohol-health/alphol-health/alphol-effects-body> (last visited Apr. 23, 2017).



never given birth or have their first child after the age of thirty are known to have an increased risk of breast and ovarian cancers.<sup>46</sup>

Scientists are also searching for biomarkers<sup>47</sup> that are associated with disease risks. For example, a study published in 2014 suggested that a blood test could be used to predict whether a person will develop dementia within two or three years.<sup>48</sup> Researchers determined that people who suffered from cognitive impairment at the time their blood was tested or within a few years of the test had lower levels of ten phospholipids.<sup>49</sup>

Furthermore, emerging science enables researchers to use data algorithms to predict certain diseases before they manifest themselves.<sup>50</sup> In July of 2014, Stanford University researchers published an algorithm that they used to predict clinical depression diagnoses up to a year in advance, based on patients' electronic health record data.<sup>51</sup> In another 2014 study, scientists relied on insurance claims data and electronic health records to determine which of a multinational corporation's 37,000 employees would develop problems related to diabetes within a year.<sup>52</sup> Likewise, IBM worked with a Virginia health system to identify patients with a risk of heart failure.<sup>53</sup> In 2016, researchers from the University of California, Los Angeles, announced that they had used data from the National Health and Nutrition Examination Survey to build a statistical model to predict prediabetes.<sup>54</sup>

Researchers are digging ever deeper for health predictors and are turning to almost limitless data sources. According to a 2016 *Wall Street Journal* article, researchers have found that employees who make purchases in bicycle shops are generally in better health than those who

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46. *Reproductive History and Cancer Risk*, NAT'L. CANCER INST. (last reviewed Nov. 9, 2016), <http://www.cancer.gov/about-cancer/causes-prevention/risk/hormones/reproductive-history-fact-sheet>; *What Are the Risk Factors for Ovarian Cancer?*, AM. CANCER SOC'Y (last revised Feb. 4, 2016), <http://www.cancer.org/cancer/ovariancancer/detailedguide/ovarian-cancer-risk-factors>; *Breast Cancer Risk and Prevention*, AM. CANCER SOC'Y, <http://www.cancer.org/cancer/breastcancer/detailedguide/breast-cancer-risk-factors> (last visited Apr. 23, 2017).

47. A "biomarker" is a "biological molecule found in blood, other body fluids, or tissues that is a sign of a normal or abnormal process, or of a condition or disease." *Biomarker*, NATIONAL CANCER INSTITUTE DICTIONARY OF CANCER TERMS, <http://www.cancer.gov/publications/dictionaries/cancer-terms?cdrid=45618> (last visited Apr. 23, 2017).

48. Alison Abbott, *Biomarkers Could Predict Alzheimer's Before It Starts*, NATURE (Mar. 9, 2014), <http://www.nature.com/news/biomarkers-could-predict-alzheimer-s-before-it-starts-1.14834>.

49. *Id.*

50. Mohana Ravindranath, *IBM Used Predictive Analytics to Find Patients at Risk of Heart Failure*, WASH. POST (Feb. 20, 2014), [https://www.washingtonpost.com/business/on-it/ibm-used-predictive-analytics-to-find-patients-at-risk-of-heart-failure/2014/02/20/9b0ddb3c-9a47-11e3-b88d-f36c07223d88\\_story.html](https://www.washingtonpost.com/business/on-it/ibm-used-predictive-analytics-to-find-patients-at-risk-of-heart-failure/2014/02/20/9b0ddb3c-9a47-11e3-b88d-f36c07223d88_story.html).

51. Arthur Allen, *Big Brother Is Watching Your Waist*, POLITICO (July 21, 2014, 5:04 AM), <http://www.politico.com/story/2014/07/data-mining-health-care-109153>.

52. *Id.*

53. *IBM Predictive Analytics to Detect Patients at Risk for Heart Failure*, IBM (Feb. 19, 2014), <http://www-03.ibm.com/press/us/en/pressrelease/43231.wss>.

54. SUSAN H. BABEY ET AL., *PREDIABETES IN CALIFORNIA: NEARLY HALF OF CALIFORNIA ADULTS ON PATH TO DIABETES I* (2016).

spend on videogames, and those who vote in midterm elections are healthier than those who do not.<sup>55</sup> By contrast, individuals with low credit scores are less likely than others to fill prescriptions and obtain follow-up care and are thus in poorer health.<sup>56</sup>

Once employers obtain predictive health information, they will likely be sorely tempted to use it in making employment decisions. Already, some employers reject candidates who are obese or smoke because of anticipated health problems.<sup>57</sup> In the future, they might disqualify applicants because of particular traits or behaviors (such as sleeping, exercise, and purchasing habits) so long as they believe that these reliably forecast future medical ailments.

## II. THE AMERICANS WITH DISABILITIES ACT

The ADA prohibits employers from discriminating based on disability. The term “disability” is defined as follows:

- (A) a physical or mental impairment that substantially limits one or more major life activities of such individual;
- (B) a record of such an impairment; or
- (C) being regarded as having such an impairment . . . .<sup>58</sup>

This definition is quite broad in scope. In order to be covered by the ADA, individuals do not need to have an actual disabling condition. The statute’s “regarded as” provision covers workers who have mental and physical impairments that are not substantially limiting and thus not severe enough to be considered disabilities,<sup>59</sup> so long as they are not “transitory and minor.”<sup>60</sup> In addition, the law covers individuals who are perfectly healthy and have no actual impairments but whom employers wrongly perceive as impaired.<sup>61</sup>

However, the ADA does not ban discrimination against individuals who have never had disabilities and are not perceived as having existing impairments but are deemed to be at risk of being unhealthy in the future.<sup>62</sup> Thus, under the ADA, employers are permitted to base employment decisions on concern that individuals will become ill in the future because of their eating habits, stress levels, exposure to toxins, or a myriad of other hazards.

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55. Silverman, *supra* note 23.

56. *Id.*

57. Jessica L. Roberts, *Healthism and the Law of Employment Discrimination*, 99 IOWA L. REV. 571, 577–79 (2014).

58. Americans with Disabilities Act, 42 U.S.C. § 12102(1) (2010).

59. *Id.* § 12102(3)(A)–(B).

60. *Id.* Transitory impairments are defined as those “with an actual or expected duration of 6 months or less,” such as a broken leg or influenza. *Id.* § 12102(3)(B).

61. *Id.* § 12102 (3)(A).

62. *See id.*

The ADA is not the only federal statute that addresses discrimination based on health-related information. The Genetic Information Nondiscrimination Act (“GINA”) prohibits employers from discriminating based on genetic information.<sup>63</sup> Thus, employers cannot legally seek genetic data, including family health histories, from applicants or employees.<sup>64</sup> They also cannot lawfully make adverse employment decisions based on determining that individuals have genetic abnormalities or family histories that render them susceptible to particular diseases that they might develop later in life.<sup>65</sup> However, GINA’s sole focus is genetic information, and it does not reach any other predictive data.

### III. RECOMMENDED ADA REVISIONS

The ADA should be amended to address serious concerns about discrimination in the era of big data. Specifically, the ADA should account for the likelihood that employers will make adverse decisions based on information that may predict that an individual will develop medical problems in the future. This approach would be consistent with that of GINA, which protects workers with disease risks because of genetic mutations.<sup>66</sup>

#### A. EXPANDING THE “REGARDED AS” PROVISION

The simplest and most logical way to amend the ADA is to add language to the “regarded as” provision of the statute.<sup>67</sup> The provision should be extended to include individuals who are perceived as likely to develop physical or mental impairments in the future. Thus, the provision would cover not only those who are perceived as being currently impaired, but also those who are perceived as being at risk of impairment in the future based on information their employers obtained about their habits, purchases, biomarkers, or other indicators. As in other “regarded as” cases, a plaintiff should not be required to prove that the employer believed she would develop a condition that rises to the level of a disability. Instead, plaintiffs should have to prove only that the employer was worried about a non-transitory physical or mental impairment.<sup>68</sup>

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63. Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, §§ 201(4), 202(a), 122 Stat. 881 (2008); Genetic Information Nondiscrimination Act of 2008, 42 U.S.C. §§ 2000ff(4), 2000ff-1(a) (2010). Genetic information is defined as including (i) an individual’s genetic tests, (ii) the genetic tests of an individual’s family members, and (iii) the manifestation of a disease or disorder in an individual’s family members. *Id.* § 2000ff(4)(A).

64. *Id.* § 2000ff-1(b).

65. *Id.* § 2000ff-1(a).

66. *Id.* §§ 2000ff(4), 2000ff-1(a).

67. *Id.* §§ 12102(1)(C), 12102(3).

68. *See supra* note 54 and accompanying text. Federal regulations define a “physical or mental impairment” as:

One might object that the proposed revision will expand ADA coverage potentially to all Americans because any worker might be subject to data mining. In truth, however, the existing “regarded as” provision is already expansive and covers anyone and everyone who is incorrectly perceived as disabled, including those who are perfectly healthy.<sup>69</sup> Thus, Congress did not intend that the ADA’s protection extend only to a “discrete and insular minority.”<sup>70</sup> Moreover, the ADA’s broad coverage is consistent with that of most other federal employment antidiscrimination laws.<sup>71</sup> Title VII of the Civil Rights Act of 1964 covers anyone who is subjected to discrimination based on race, color, religion, sex, or national origin, including males and whites.<sup>72</sup> The Equal Pay Act prohibits sex-based wage discrimination against both men and women.<sup>73</sup> Likewise, GINA protects all individuals against discrimination based on genetic information.<sup>74</sup>

### I. *Overlap with GINA*

The proposed amendment would overlap with GINA to some degree. It would cover employer discrimination stemming from concerns about future impairments, whether or not such concerns are based on genetic information. Workers whose employers unlawfully purchase or obtain genetic information by requiring them to provide genetic samples or family medical histories could file claims under GINA even if the data collection did not lead to any discrimination.<sup>75</sup> However, those who believe employers obtained genetic information and then proceeded to exclude them from job opportunities because of concerns about future

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(1) Any physiological disorder or condition, cosmetic disfigurement, or anatomical loss affecting one or more body systems, such as neurological, musculoskeletal, special sense organs, respiratory (including speech organs), cardiovascular, reproductive, digestive, genitourinary, immune, circulatory, hemic, lymphatic, skin, and endocrine; or

(2) Any mental or psychological disorder, such as an intellectual disability (formerly termed “mental retardation”), organic brain syndrome, emotional or mental illness, and specific learning disabilities.

29 C.F.R. § 1630.2(h) (2015).

69. See *supra* notes 53–55 and accompanying text.

70. See Sharon Hoffman, *The Importance of Immutability in Employment Discrimination Law*, 52 WM. & MARY L. REV. 1483, 1500–04 (2011) (critiquing the theory that the employment discrimination laws are designed to protect discrete and insular minorities).

71. The only federal antidiscrimination in employment law that explicitly limits its protected class is the Age Discrimination in Employment Act, which covers only individuals who are forty or older. Age Discrimination in Employment Act of 1967, 29 U.S.C. § 631(a) (2012).

72. 42 U.S.C. § 2000e-2.

73. Equal Pay Act of 1963, 29 U.S.C. § 206(d)(1) (2012).

74. 42 U.S.C. § 2000ff-4(a).

75. *Id.* § 2000ff-1(a) (prohibiting employment discrimination because of genetic information); *Id.* § 2000ff-1(b) (“It shall be an unlawful employment practice for an employer to request, require, or purchase genetic information with respect to an employee or a family member of the employee . . .”).

medical disorders could sue under both GINA and the ADA's new provision.

This would not be the only overlap among antidiscrimination laws. Employees who believe they have been subjected to wage discrimination because of their sex can sue under both the Equal Pay Act<sup>76</sup> and Title VII of the Civil Rights Act of 1964.<sup>77</sup> Similarly, individuals who believe they are victims of race discrimination can sue under both Title VII and section 1981 of the Civil Rights Act of 1866.<sup>78</sup>

It would make little sense to exclude inherited conditions from the new ADA provision. Plaintiffs often will not know whether employers obtained genetic information or some other type of information that has made them concerned about the individual's vulnerabilities to future diseases. Moreover, employers are unlikely to analyze disease etiology in making employment decisions. If they choose to discriminate because of concern about individuals' future health conditions, they will do so regardless of whether the anticipated illnesses are genetic in origin, and they may well be unaware of whether there are any genetic factors associated with the disease.

## 2. *Exceptions for Risk-Taking Behaviors*

At times human beings intentionally engage in risk-taking behavior, knowing that the conduct can lead to future disabilities.<sup>79</sup> The proposed statutory amendment could take account of risk-taking behavior that is within individuals' control. The provision could explicitly allow employers to take adverse action against applicants and employees because of specific intentional activities.<sup>80</sup> For example, some employers decline to hire candidates who smoke, and legislators may decide to allow employers to continue this practice.<sup>81</sup> It should be noted, however, that some studies have found that smoking initiation and addiction are genetically-driven

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76. 29 U.S.C. § 206(d)(1).

77. Civil Rights Act of 1964, 42 U.S.C. § 2000e-2(a) (2012).

78. *Id.*; Civil Rights Act of 1866, 42 U.S.C. § 1981 (2012).

79. *See supra* note 41 and accompanying text.

80. Note that employers could not reject or terminate individuals for alcoholism. Alcoholics are protected by the ADA, and the statute permits employers to terminate individuals only for drinking alcohol in the workplace or being under the influence of alcohol at work. 42 U.S.C. §§ 12114(c)(1), (2) (2012); *Questions and Answers: The Americans with Disabilities Act and Hiring Police Officers*, U.S. DEP'T OF JUST. (Mar. 25, 1997), <https://www.ada.gov/copsq7a.htm>.

81. Roberts, *supra* note 57, at 577-79; A. G. Sulzberger, *Hospitals Shift Smoking Bans to Smoker Ban*, N.Y. TIMES (Feb. 10, 2011), [http://www.nytimes.com/2011/02/11/us/11smoking.html?\\_r=0](http://www.nytimes.com/2011/02/11/us/11smoking.html?_r=0); CLEVELAND CLINIC, NEW NONSMOKING HIRING POLICY AT CLEVELAND CLINIC, [https://my.clevelandclinic.org/ccf/media/files/Urology/Non-Smoking\\_Hiring\\_Statement.pdf](https://my.clevelandclinic.org/ccf/media/files/Urology/Non-Smoking_Hiring_Statement.pdf) (last visited Apr. 23, 2017). The Cleveland Clinic offers smoking cessation programs at no cost to rejected applicants for residency and fellowship positions. It states that, at its discretion, it may reconsider these applicants if they successfully complete a program. *Id.*

to some extent.<sup>82</sup> As scientists achieve greater certainty about the degree to which substance dependence is or is not a matter of individual free will, the exemption provision may need to be revised accordingly.<sup>83</sup>

Legislators should list particular behaviors that will be exempted from the antidiscrimination mandate rather than create an exception for all “risk-taking behavior” or a similarly worded classification. A broad exemption would allow employers to reject or terminate workers because they ski, eat sweets, or are women who have not had children, since all of these are associated with health risks.<sup>84</sup> By contrast, a list of specific activities that employers can consider for purposes of decisionmaking would provide employers with clear guidance and greatly limit disputes and the need for judicial interpretation.

### 3. Obesity

Workplace advocates have long asserted that obese workers are frequent victims of employment discrimination.<sup>85</sup> The proposed provision should be of assistance to obese individuals. Individuals can take measures such as healthy eating and exercise to manage their weight to some degree.<sup>86</sup> Yet, science has shown that obesity is often not within the realm of individuals’ control. Rather, genetic factors are strongly linked to body-mass index,<sup>87</sup> and “obesity may be considered a disease initiated by a complex interaction of genetics and the environment.”<sup>88</sup> Consequently, the new ADA provision should not include an exemption for employment decisions that are based on obesity.

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82. Laura Jean Bierut, *Genetic Vulnerability and Susceptibility to Substance Dependence*, 69 NEURON 618, 618–20 (2011); Matt McGue et al., *The Adolescent Origins of Substance Use Disorders: A Behavioral Genetic Perspective*, 61 NEB. SYMP. MOTIVATION 31, 45–47 (2014); Jen-Chyong Wang et al., *The Genetics of Substance Dependence*, 13 ANN. REV. GENOMICS HUM. GENETICS 241, 247–50 (2012).

83. If discrimination against smokers were to be prohibited, employers could not simply discharge their nondiscrimination duties by offering all smokers smoking cessation programs because these programs are not uniformly effective. See Nagihan Durmus Kocak et al., *Relapse Rate and Factors Related to Relapse in a 1-Year Follow-Up of Subjects Participating in a Smoking Cessation Program*, 60 RESPIRATORY CARE 1796, 1796 (2015) (“The relapse rate in a 1-y period was 51.4%.”); Koshi Nakamura et al., *Nicotine Dependence and Cost-Effectiveness of Individualized Support for Smoking Cessation: Evidence from Practice at a Worksite in Japan*, 8 PLoS ONE (2013), <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3559493/#pone.0055836-Berterai> (following 151 subjects who stopped smoking after voluntarily entering a smoking cessation program and finding that “[o]ver the 24-month study period, self-report showed 49.7% abstained continuously from smoking.”).

84. Women who have not had children have a higher risk of breast and ovarian cancer. See *supra* note 40 and accompanying text.

85. Hoffman, *supra* note 70, at 1531–33; Jane Korn, *Too Fat*, 17 VA. J. SOC. POL’Y & L. 209, 221 (2010).

86. Krista Casazza et al., *Myths, Presumptions, and Facts About Obesity*, 368 NEW ENG. J. MED. 446, 446–54 (2013); Thomas A. Wadden et al., *Behavioral Treatment of Obesity in Patients Encountered in Primary Care Settings: A Systematic Review*, 312 JAMA 1779, 1779–91 (2014).

87. Adam E. Locke et al., *Genetic Studies of Body Mass Index Yield New Insights for Obesity Biology*, 518 NATURE 197, 197 (2015).

88. Caroline M. Apovian, *The Obesity Epidemic—Understanding the Disease and the Treatment*, 374 NEW ENG. J. MED. 177, 178 (2016).

Employers would thus be precluded from excluding obese individuals from jobs because of concern that they will develop impairments and raise health insurance costs in the future. Admittedly, employers would still be able to take adverse action that is not based on concern about obese individuals' future health problems. The federal antidiscrimination laws do not prohibit appearance-based discrimination, and only a handful of states ban it.<sup>89</sup> It is also true that it is often very difficult for plaintiffs to identify and prove the reason for the employer's adverse decision,<sup>90</sup> and some employers might falsely but vigorously deny that they considered health risks. Nevertheless, obese workers may face less discrimination and enjoy more job opportunities as conscientious employers learn to comply with the new ADA mandate.

## B. DISCLOSING DATA MINING PRACTICES

Standing alone, an ADA provision that prohibits employment discrimination based on predictions of future impairments will not provide adequate protection for workers. This is because applicants and employees may never discover that an employer used data mining or data broker services to obtain predictive information about them and thus will not be able to garner evidence to establish discrimination cases.

In order to provide meaningful protection, therefore, the ADA will need to include a requirement that employers disclose their use of big data. The ADA features an extensive medical inquiry and exam provision that governs how and when employers can obtain medical information about workers.<sup>91</sup> The provision should be revised to add a mandate that employers provide written disclosure to applicants and employees of any practices other than medical exams and direct medical inquiries by which they seek health-related information, including information from which they may draw conclusions about an individual's future health status. Government enforcement agencies such as the Equal Employment Opportunity Commission ("EEOC")<sup>92</sup> and plaintiffs'

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89. See D.C. CODE ANN. §§ 2-1401.02(22), 2-1402.11(a) (2001) (prohibiting discrimination based on personal appearance); MICH. COMP. LAWS § 37.2202 (2006) (prohibiting discrimination based on height and weight); Deborah L. Rhode, *Hooters Hires Based on Looks. So Do Many Companies. And There's No Law Against It.*, NEW REPUBLIC (Aug. 30, 2014), <https://newrepublic.com/article/118683/why-we-need-law-protect-against-appearance-discrimination>.

90. Gwen Moran, *Here's What It Takes to Sue for Gender Pay Discrimination—and Win*, FORTUNE (Apr. 12, 2016), <http://fortune.com/2016/04/12/how-to-sue-for-gender-pay-discrimination/>; Penelope Lemov, *What It Takes To Win An Age Discrimination Suit*, FORBES (Apr. 30, 2013, 10:06 AM), <http://www.forbes.com/sites/nextavenue/2013/04/30/what-it-takes-to-win-an-age-discrimination-suit/#5751ffff66e1>.

91. Americans with Disabilities Act, 42 U.S.C. § 12112(d) (2012).

92. The Equal Employment Opportunity Commission is the federal agency tasked with enforcing the federal antidiscrimination laws. See *Overview*, U.S. EQUAL EMP. OPPORTUNITY COMMISSION, <http://www.eeoc.gov/eeoc/> (last visited Apr. 23, 2017).

attorneys that receive complaints from aggrieved workers could then investigate whether these activities resulted in unlawful discrimination.

A disclosure requirement would not open the floodgates of litigation. In order to prevail, a plaintiff would need to show far more than that the employer engaged in data mining or sought information from data brokers. She would need to have evidence that the employer actually discovered health predictive information and then based an adverse decision on that data rather than on any of a myriad of other factors, such as the worker's job qualifications, impressions made during an interview, and job performance.<sup>93</sup> Thus, plaintiffs would still face an uphill battle, and employers' disclosures are unlikely to lead to significant increases in court filings and frivolous litigation.

### CONCLUSION

In the era of big data, employers will be able to obtain growing treasure troves of information about their applicants and employees.<sup>94</sup> Because employers have much to gain from minimizing the number of sick employees in their workforces, they may attempt to use big data to identify and exclude individuals who are at risk of developing health problems.

To address this potential form of discrimination, Congress should amend the ADA's "regarded as" provision to prohibit discrimination based on concern that an individual is likely to develop a physical or mental impairment in the future. Furthermore, the statute should be revised to require employers to provide written disclosure of any practices other than medical exams and direct medical inquiries by which they seek health-related information.<sup>95</sup>

It should be noted that all discrimination cases are difficult to prove.<sup>96</sup> Employers can always claim that their adverse decision was based on a bad interview, having more qualified applicants, suboptimal performance, or personality conflicts in the workplace and these claims are often hard to refute. A few well-publicized plaintiffs' victories, however, can go far to deter employer misconduct. Moreover, the great hope of the antidiscrimination laws is that the vast majority of employers are law-abiding and wish to comply with regulatory mandates. Consequently, in light of the added ADA provision, they will voluntarily avoid basing employment decisions on worries that individuals will become sick and thus costly in the future.

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93. See *supra* note 89 and accompanying text.

94. See *supra* Part II.

95. See *supra* Part III.

96. See Sharon Hoffman, *Settling the Matter: Does Title I of the ADA Work?*, 59 ALA. L. REV. 305, 308-09 (2008); see also *supra* note 85 and accompanying text.



This suggested approach will balance the needs of employers to retain decisionmaking autonomy with the needs of workers to have antidiscrimination protections. It is a compromise between banning employers' data mining practices altogether and ignoring them. It will also promote greater consistency between the ADA and GINA as both statutes would address discrimination based on predictive health information. Most importantly, these amendments will align the law with rapidly evolving developments in data science and technology and will prevent it from becoming outdated and unresponsive to new workplace vulnerabilities.

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