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# Big Data and the Americans with Disabilities Act: Amending the Law to Cover Discrimination Based on Data-Driven Predictions of Future Illnesses

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*Draft*

## **Big Data’s New Discrimination Threats: Amending the Americans with Disabilities Act to Cover Discrimination Based on Data-Driven Predictions of Future Disease**

Forthcoming in Glenn Cohen, Allison Hoffman and William Sage (eds.), *Big Data, Health Law, and Bioethics* (Cambridge University Press 2017)

**Sharona Hoffman\***

While big data holds great promise to improve the human condition, it also creates new and previously unimaginable opportunities for discrimination. Employers, financial institutions, marketers, educational institutions, and others can now easily obtain a wealth of big data about individuals’ health status and use it to make adverse decisions relating to data subjects.<sup>1</sup>

The Americans with Disabilities Act (ADA) is a federal law that prohibits employers and other public and private entities from discriminating against individuals because of their disabilities.<sup>2</sup> This chapter argues that in the era of big data, the ADA does not go far enough. While the ADA protects individuals who have existing disabilities, records of past disabilities, or are regarded as having mental or physical impairments, it does not reach people who are currently healthy but are perceived as being at high risk of becoming sick in the future. This is a gap that should not be ignored at a time when decision-makers have many newly-available data tools that enable them to make predictions about medical problems that individuals will face in later years.

The chapter recommends that the ADA be amended to expand its anti-discrimination mandate. Specifically, the statute should 1) prohibit discrimination based on predictions of future physical or mental impairments and 2) require covered entities to disclose in writing their use of big data or other non-traditional means to obtain health-related information.<sup>3</sup>

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<sup>1</sup> Sharona Hoffman, *Citizen Science: The Law and Ethics of Public Access to Medical Big Data*, 30 *Berkeley Technology Law Journal*, 1741, 1773-80 (2015); John Podesta et al., *Big Data: Seizing Opportunities, Preserving Values* 51-53 (May 2014), at [https://www.whitehouse.gov/sites/default/files/docs/big\\_data\\_privacy\\_report\\_may\\_1\\_2014.pdf](https://www.whitehouse.gov/sites/default/files/docs/big_data_privacy_report_may_1_2014.pdf).

<sup>2</sup> Americans with Disabilities Act of 1990. Public Law 101-336. 108th Congress, 2nd session (July 26, 1990) (codified primarily in 42 U.S.C. §§ 12101-12213 (2010)).

<sup>3</sup> Non-traditional means are means other than medical exams or inquiries.

## I. Who Might Be Interested in Medical Big Data?

A variety of parties are likely to have an interest in individuals' predictive health data. Among them are employers, financial institutions, marketers and educational institutions.

First and foremost, employers are highly motivated to hire the healthiest possible employees. Employers hope to avoid absenteeism problems, productivity problems, and most importantly, high health care and health insurance costs. Some employers already reject candidates who are obese or smoke because of anticipated health problems.<sup>4</sup> Consequently, employers will likely be keen to obtain further information that will allow them to determine which applicants and employees will develop serious illnesses in the future for purposes of employment decisions.

Likewise, financial institutions are eager to collect information about individuals who seek their services. Banks routinely maintain databases with data about customers who previously overdrew their accounts or bounced checks.<sup>5</sup> In the future, if it is easily available, financial institutions may well add health information to their databases in order to improve their ability to screen out applicants with a high risk of defaulting on loans because of medical difficulties.

Marketers and advertisers have a similar interest in individuals' health data. The more they know about potential customers, the more accurately they can tailor their materials to appeal to particular consumers or determine who should and who should not receive various offers.<sup>6</sup> A 2014 Presidential report explained marketers' pricing practices as follows:

[S]ome . . . retailers were found to be using an algorithm that generated different discounts for the same product to people based on where they believed the customer was located. While it may be that the price differences were driven by the lack of competition in certain neighborhoods, in practice, people in higher-income areas received higher discounts than people in lower-income areas.<sup>7</sup>

Similarly, individuals who are perceived as being at high risk of imminent illness may not receive generous promotional offers because marketers will assume they will not be devoted customers and big spenders in the long-term. Retailers have developed considerable skill in collecting and analyzing health-related data as demonstrated by a 2012 Forbes magazine article entitled "How Target Figured Out A Teen Girl Was Pregnant Before Her Father Did."<sup>8</sup>

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<sup>4</sup> Jessica L. Roberts, Healthism and the Law of Employment Discrimination, 99 Iowa Law Review 571, 577-79 (2014).

<sup>5</sup> Jessica Silver-Greenberg & Michael Corkery, Bank Account Screening Tool is Scrutinized as Excessive, New York Times (June 15, 2014), <http://dealbook.nytimes.com/2014/06/15/bank-account-screening-tool-is-scrutinized-as-excessive>.

<sup>6</sup> Lori Andrews, Facebook is Using You, New York Times (Feb. 4, 2012), <http://www.nytimes.com/2012/02/05/opinion/sunday/facebook-is-using-you.html>.

<sup>7</sup> Executive Office of the President, Big Data: Seizing Opportunities, Preserving Values, 46-47 (2014), [http://www.whitehouse.gov/sites/default/files/docs/big\\_data\\_privacy\\_report\\_may\\_1\\_2014.pdf](http://www.whitehouse.gov/sites/default/files/docs/big_data_privacy_report_may_1_2014.pdf).

<sup>8</sup> Kashmir Hill, How Target Figured Out a Teen Girl Was Pregnant Before Her Father Did, Forbes (Feb. 16, 2012), <http://www.forbes.com/sites/kashmirhill/2012/02/16/how-target-figured-out-a-teen-girl-was-pregnant-before-her->

It is even possible that financially-focused educational institutions would be interested in big data medical information about applicants. Universities hope to enroll students who will become successful professionals, bring honor to the school, and donate generously for many years. Therefore, applicants who are likely to have abbreviated careers and limited earnings because of medical challenges may be unappealing prospects to some institutions of higher learning.

## II. The Many Sources of Health-Related Big Data

Employers, financial institutions, marketers, universities, and others may obtain health-related big data from a myriad of sources. By “health-related big data” I mean both medical data itself and other types of data from which analysts may infer information about individuals’ health. Several data sources are discussed below.

### A. Social Media

Facebook, Twitter, Instagram, and other social media platforms provide a treasure-trove of information, including medical data, for interested parties. Many users post personal and sensitive details about themselves and are not scrupulous about their privacy settings.

An online article entitled *How Social Media Strengthens Your Loan Application* informs borrowers that a “growing number of lenders—mostly online lenders—are using social media as part of their loan underwriting process.”<sup>9</sup> A different article, entitled *Lots More College Admissions Officers Are Checking Your Instagram and Facebook*, cautions the public that “fully 40 percent of admissions officers say they visit applicants’ social media pages to learn about them.”<sup>10</sup>

Employers are particularly notorious in this regard. According to CareerBuilder’s annual social media recruitment survey of more than 2,000 hiring managers, sixty percent of employers acknowledged that they read job candidates’ social networking sites in the process of assessing them.<sup>11</sup> Moreover, employers do in fact base adverse decisions on information that they discover on social media.<sup>12</sup> For example, one employer terminated an employee for abusing his leave

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father-did (discussing Target’s practice of data-mining its customers’ purchasing records in order “to figure out what you like, what you need, and which coupons are most likely to make you happy”).

<sup>9</sup> Rieva Lesonsky, *How Social Media Strengthens Your Loan Application*, FunderaLedge, July 13, 2015, <https://www.fundera.com/blog/2015/07/13/how-social-media-strengthens-your-loan-application>.

<sup>10</sup> Kaitlin Mulhere, *Lots More College Admissions Officers Are Checking Your Instagram and Facebook*, Time, January 13, 2016, <http://time.com/money/4179392/college-applications-social-media/>.

<sup>11</sup> CareerBuilder, *Number of Employers Using Social Media to Screen Candidates Has Increased 500 Percent over the Last Decade*, April 28, 2016,

[http://www.careerbuilder.com/share/aboutus/pressreleasesdetail.aspx?sd=4/28/2016&siteid=cbpr&sc\\_cmp1=cb\\_pr945\\_&id=pr945&ed=12/31/2016](http://www.careerbuilder.com/share/aboutus/pressreleasesdetail.aspx?sd=4/28/2016&siteid=cbpr&sc_cmp1=cb_pr945_&id=pr945&ed=12/31/2016).

<sup>12</sup> Steven L. Thomas et al., *Social Networking, Management Responsibilities, and Employee Rights: The Evolving Role of Social Networking in Employment Decisions*, 27 *Employee Responsibilities & Rights Journal* 307, 307 (2015).

time after finding photos that the worker posted from vacations he took while on medical leave following shoulder surgery.<sup>13</sup>

## B. Wellness Programs

Wellness programs are increasingly popular among employers who hope to improve employees' health and thereby save healthcare costs.<sup>14</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>15</sup> These programs routinely require participants to disclose details about their health either directly to employers or to wellness vendors, who may share certain information with employers and enable them to make adverse decisions about applicants and employees.<sup>16</sup>

## C. Data Brokers

A growing industry of data brokers is operating in the United States, collecting personal information from a variety of public and private sources and selling it to interested parties.<sup>17</sup> Data brokers mine sources such as social media, personal websites, U.S. Census records, state hospital records, retailers' purchasing records, real property records, insurance claims, and more.<sup>18</sup> They are known to sell lists of people with sexually transmitted diseases, Alzheimer's, dementia, AIDS, depression, and other ailments.<sup>19</sup> By some estimates, several thousand data brokers already exist, including well-known companies such as Spokeo and Axiom.<sup>20</sup>

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<sup>13</sup> Jones v. Gulf Coast Health Care of Delaware, LLC, 2016 WL 659308 (M.D. Fla. Feb. 18, 2016).

<sup>14</sup> Reed Abelson, Employee Wellness Programs Use Carrots, and Increasingly, Sticks, New York Times, Jan. 24, 2016, available at [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).

<sup>15</sup> Kaiser Family Foundation, 2016 Employer Health Benefits Survey, September 14, 2016, <http://kff.org/report-section/ehbs-2016-summary-of-findings/>.

<sup>16</sup> Jay Hancock, Workplace Wellness Programs Put Employee Privacy at Risk, CNN, October 2, 2015, <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 Street Journal, February 17, 2016, available at <http://www.wsj.com/articles/bosses-harness-big-data-to-predict-which-workers-might-get-sick-1455664940>; How to Set Up a Wellness Plan, Wall Street Journal, Sept. 12, 2008, at <http://guides.wsj.com/small-business/hiring-and-managing-employees/how-to-set-up-a-wellness-plan/tab/print/>.

<sup>17</sup> Brian Naylor, Firms Are Buying, Sharing Your Online Info. What Can You Do About It?, NPR, July 11, 2016, <http://www.npr.org/sections/alltechconsidered/2016/07/11/485571291/firms-are-buying-sharing-your-online-info-what-can-you-do-about-it>.

<sup>18</sup> Gary Anthes, Data Brokers Are Watching You, 58 Communications of the ACM 28, 28-30 (2015) <http://cacm.acm.org/magazines/2015/1/181629-data-brokers-are-watching-you/fulltext>.

<sup>19</sup> Frank Pasquale, The Dark Market for Personal Data, New York Times, Oct. 16, 2014, available at [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).

<sup>20</sup> Id.; Paul Boutin, The Secretive World of Data Brokers, Newsweek, May 30, 2016, <http://www.newsweek.com/secretive-world-selling-data-about-you-464789>; Spokeo, last visited July 4, 2016, [http://www.spokeo.com/?g=name\\_gs\\_C000213&gclid=CK617oWG-MoCFYsAaQod2moCkQ](http://www.spokeo.com/?g=name_gs_C000213&gclid=CK617oWG-MoCFYsAaQod2moCkQ); Axiom, last visited July 4, 2016, <http://www.axiom.com/>.

Lenders turn to data brokers in order to purchase information that identifies financially distressed consumers.<sup>21</sup> Likewise, marketers commonly use the services of data brokers. For example, according to one source, each year “Pfizer spends \$12 million to buy health data from a variety of sources.”<sup>22</sup>

Employers too have not shied away from the offerings of data brokers. Walmart reportedly hired a company called Castlight to identify workers with back problems and those who are likely to become pregnant, purportedly in order to give them advice about good health care.<sup>23</sup> It takes little imagination, however, to conclude that employers could also use such information for discriminatory purposes.

#### **D. Open Data Sources**

The federal government, state governments, and private sector entities have established numerous large databases that offer the public access to patient-related health information.<sup>24</sup> For instance, the Centers for Disease Control and Prevention’s CDC Wonder allows users to search for a broad range of health information. Thus, one can search for cancer incidence by “year, state, metropolitan area, age group, race, ethnicity, gender, childhood cancers and cancer site classifications.”<sup>25</sup>

Similar data can be garnered from The Healthcare Cost and Utilization Project (HCUP) databases. These offer “a core set of clinical and nonclinical information found in a typical [hospital] discharge abstract including all-listed diagnoses and procedures, discharge status, patient demographics, and charges for all patients.”<sup>26</sup>

Employers, lenders, and others may use these demographic and other data to create profiles of individuals who are particularly vulnerable to certain diseases, such as cancer. They then may make adverse decisions concerning people that fit those profiles.

#### **E. What about Privacy Protections?**

One might wonder why so much health information is widely available despite the existence of the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule. The answer is that the HIPAA Privacy Rule is limited in its reach. It covers only health care providers,

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<sup>21</sup> Stephanie Armour, Data Brokers Come under Fresh Scrutiny: Consumer Profiles Marketed to Lenders, *The Wall Street Journal*, February 12, 2014, <http://www.wsj.com/articles/SB10001424052702303874504579377164099831516>.

<sup>22</sup> Adam Tanner, How Data Brokers Make Money Off Your Medical Records, *Scientific American*, February 1, 2016, <https://www.scientificamerican.com/article/how-data-brokers-make-money-off-your-medical-records/>.

<sup>23</sup> Rachel Emma Silverman, Bosses Tap Outside Firms to Predict Which Workers Might Get Sick, *Wall Street Journal*, February 17, 2016, available at <http://www.wsj.com/articles/bosses-harness-big-data-to-predict-which-workers-might-get-sick-1455664940>; Aimee Picchi, The "Big Data" App that Predicts Employees' Health, *CBS News*, February 18, 2016, <http://www.cbsnews.com/news/the-big-data-app-that-predicts-employees-health/>.

<sup>24</sup> Hoffman, *supra* note 1, at 1748-54.

<sup>25</sup> Centers for Disease Control and Prevention, United States Cancer Statistics Public Information Data, last reviewed August 15, 2016, <https://wonder.cdc.gov/cancer.html>.

<sup>26</sup> Databases and Related Tools from HCUP: Fact Sheet, Agency for Healthcare Research and Quality, at <http://archive.ahrq.gov/research/findings/factsheets/tools/hcupdata/datahcup.html>.



insurers, health care clearinghouses, and their business associates.<sup>27</sup> Therefore, many of those who produce and handle medical big data, including social media operators, wellness vendors, data miners, and government entities, are not governed by HIPAA.

In addition, the HIPAA Privacy Rule protects only “individually identifiable health information.”<sup>28</sup> The Rule, therefore, does not govern de-identified data,<sup>29</sup> and many big data sources are de-identified at least to some extent.<sup>30</sup> Finally, it covers only “protected health information,” and thus, non-medical data that are used to make health predictions or determinations are exempted from the regulations.<sup>31</sup> Consequently, the HIPAA Privacy Rule does not significantly infringe upon the big data market.

### III. Health-Related Big Data and Disease Prediction

Big data is useful to employers, lenders, educators, marketers, and others because it can enable them to make predictions about individuals’ future health status. Increasingly, scientists are recognizing that particular behaviors or traits render individuals vulnerable to future ailments.<sup>32</sup> The most obvious example is smoking, which is associated with risks of various cancers, heart disease, stroke, and other serious conditions.<sup>33</sup> Alcoholism is associated with impairments of the heart, liver, pancreas, and other systems.<sup>34</sup> Women who never bore children or have their first child when they are older than thirty are at increased risk of breast and ovarian cancers.<sup>35</sup>

Medical researchers are also pursuing biomarkers that can help them identify disease risks. A “biomarker” is a “biological molecule found in blood, other body fluids, or tissues that is a

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<sup>27</sup> 45 C.F.R. §§ 160.102-160.103 (2016); 42 U.S.C. §17934 (2010).

<sup>28</sup> 45 C.F.R. § 160.103 (2016).

<sup>29</sup> See 45 C.F.R. § 164.514(b) (2016) for details regarding de-identification.

<sup>30</sup> Tanner, *supra* note 22 (stating that “data brokers are not restricted by medical privacy rules in the U.S., because their records are designed to be anonymous—containing only year of birth, gender, partial zip code and doctor’s name”); Jay Hancock, *Workplace Wellness Programs Put Employee Privacy at Risk*, CNN, October 2, 2015, <http://www.cnn.com/2015/09/28/health/workplace-wellness-privacy-risk-exclusive/> (explaining that “HIPAA [does not] protect the de-identified health information that wellness providers routinely share with employers and other, unidentified outside parties . . . include[ing] blood pressure, cholesterol, drug use and disease history.”).

<sup>31</sup> 45 C.F.R. § 160.103 (2016) (defining protected health information).

<sup>32</sup> Francie Diep, *How to Predict a Lifetime of Diseases*, *Popular Science*, June 24, 2014, available at <http://www.popsoci.com/article/science/how-predict-lifetime-diseases>.

<sup>33</sup> National Heart, Lung, and Blood Institute, *What Are the Risks of Smoking?* last visited July 4, 2016, <https://www.nhlbi.nih.gov/health/health-topics/topics/smo/risks>; National Cancer Institute, *Harms of Cigarette Smoking and Health Benefits of Quitting*, last visited July 4, 2016, <http://www.cancer.gov/about-cancer/causes-prevention/risk/tobacco/cessation-fact-sheet>.

<sup>34</sup> National Institute on Alcohol Abuse and Alcoholism, *Alcohol’s Effects on the Body*, last visited July 4, 2016, <http://www.niaaa.nih.gov/alcohol-health/alcohols-effects-body>.

<sup>35</sup> National Cancer Institute, *Reproductive History and Breast Cancer Risk*, last visited July 4, 2016, <http://www.cancer.gov/about-cancer/causes-prevention/risk/hormones/reproductive-history-fact-sheet>; American Cancer Society, *What Are the Risk Factors for Ovarian Cancer?* (2016) <http://www.cancer.org/cancer/ovariancancer/detailedguide/ovarian-cancer-risk-factors>; American Cancer Society, *What Are the Risk Factors for Breast Cancer?* (2016) at <http://www.cancer.org/cancer/breastcancer/detailedguide/breast-cancer-risk-factors>.

sign of a normal or abnormal process, or of a condition or disease.”<sup>36</sup> For example, in a study published in 2014, researchers determined that people with lower levels of ten phospholipids in their blood were more likely than others to be suffering from cognitive impairments either at the time of the blood draw or within a few years.<sup>37</sup>

Emerging science further enables researchers to use data algorithms to predict certain diseases before the patient becomes symptomatic.<sup>38</sup> Researchers have published algorithms used to predict clinical depression, diabetes, and heart failure based on patients’ medical record data, insurance claims, and other sources.<sup>39</sup>

Researchers are becoming ever-more-creative in excavating data sources in order to discover health predictors. The *Wall Street Journal* reported findings that bicycle shop customers are generally in good health and midterm election voters are healthier than their non-voting counterparts.<sup>40</sup> By contrast, individuals with low credit scores are in poorer health than others because they are less likely to fill prescriptions and get follow-up care.<sup>41</sup>

If employers, lenders, marketers, educators, or others obtain predictive health information about individuals, they will likely be sorely tempted to use the data for decision-making purposes. It is known that some employers already reject candidates who are obese or smoke because of anticipated health problems.<sup>42</sup> In the future, entities might disqualify applicants because of a variety of traits or behaviors (e.g. sleeping, exercise, and purchasing habits) that are believed to forecast future medical ailments.

#### IV. The Americans with Disabilities Act

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<sup>36</sup> National Cancer Institute, NCI Dictionary of Cancer Terms, last visited July 4, 2016, <http://www.cancer.gov/publications/dictionaries/cancer-terms?cdrid=45618>.

<sup>37</sup> Alison Abbott, Biomarkers Could Predict Alzheimer's before It Starts, *Nature*, March 9, 2014, available at <http://www.nature.com/news/biomarkers-could-predict-alzheimer-s-before-it-starts-1.14834>.

<sup>38</sup> Mohana Ravindranath, IBM Used Predictive Analytics to Find Patients at Risk of Heart Failure, *Washington Post*, February 20, 2014, available at [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).

<sup>39</sup> Arthur Allen, Big Brother is Watching Your Waist, *Politico*, July 21, 2014, <http://www.politico.com/story/2014/07/data-mining-health-care-109153>; IBM, IBM Predictive Analytics to Detect Patients at Risk for Heart Failure, IBM News Release, Feb., 19, 2014, <http://www-03.ibm.com/press/us/en/pressrelease/43231.wss>; Susan H. Babey et al., Prediabetes in California: Nearly Half of California Adults on Path to Diabetes, UCLA Center for Health Policy Research Health Policy Brief (March 2016), <http://healthpolicy.ucla.edu/publications/Documents/PDF/2016/prediabetes-brief-mar2016.pdf> (using data from the National Health and Nutrition Examination Survey).

<sup>40</sup> Rachel Emma Silverman, Bosses Tap Outside Firms to Predict Which Workers Might Get Sick, *Wall Street Journal*, February 17, 2016, available at <http://www.wsj.com/articles/bosses-harness-big-data-to-predict-which-workers-might-get-sick-1455664940>.

<sup>41</sup> *Id.*

<sup>42</sup> Jessica L. Roberts, Healthism and the Law of Employment Discrimination, 99 IOWA L. REV. 571, 577-79 (2014).



The ADA prohibits disability-based discrimination. Title I of the statute applies to employers, Title II relates to public services, and Title III governs “public accommodations and services provided by private entities.”<sup>43</sup> The anti-discrimination mandate is straight-forward. For example, Title III provides that “[n]o individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation by any person who owns, leases (or leases to), or operates a place of public accommodation.”<sup>44</sup> Such discrimination includes “the imposition or application of eligibility criteria that screen out or tend to screen out” individuals with disabilities.<sup>45</sup>

The question of what does and does not constitute a disability is a more complicated matter. 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>46</sup>

This definition is quite broad in scope. Individuals can be covered by the ADA even if they do not have existing disabling conditions. They are covered so long as they have records of past disabilities or are wrongly perceived as having disabilities. Moreover, individuals are covered under the statute’s “regarded as” provision so long as they have any mental or physical impairment that is not “transitory and minor.”<sup>47</sup> For purposes of the “regarded as” provision, impairments do not need to substantially limit a major life activity, and thus, they need not be severe enough to be considered disabilities.<sup>48</sup>

Nevertheless, in the era of big data, the definition of disability is not broad enough. This is because the ADA does not reach predictions of future disabilities. It does not forbid 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 later in life.<sup>49</sup> Consequently, the ADA does not stop decision-makers from basing determinations on concern

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<sup>43</sup> 42 U.S.C. §§ 12111-12189 (2010).

<sup>44</sup> 42 U.S.C. § 12182 (2010). Title III “public accommodations” include banks, insurance offices, private educational institutions, sales establishments, service establishments, and many other private entities. 42 U.S.C. § 12181(7). Note that public colleges and universities are covered under Title II, which applies to public services. 42 U.S.C. § 12131 (defining a “public entity” as including any instrumentality of a state or local government).

<sup>45</sup> 42 U.S.C. § 12182(b)(2)(A)(i) (2010). Such eligibility criteria are not unlawfully discriminatory if they “can be shown to be necessary for the provision of the goods, services, facilities, privileges, advantages, or accommodations being offered.”

<sup>46</sup> 42 U.S.C. § 12102 (2010).

<sup>47</sup> 42 U.S.C. § 12102(3)(B) (2010). Transitory impairments are defined as those “with an actual or expected duration of 6 months or less,” such as a broken leg or influenza.

<sup>48</sup> 42 U.S.C. § 12102 (3) (A) (2010).

<sup>49</sup> See *id.*

that individuals will become ill in the future because of their health habits, stress levels, exposure to environmental pollutants, or a multitude of other hazards.

Note that the Genetic Information Nondiscrimination Act (GINA) prohibits employers and health insurers (but not others) from discriminating based on genetic information.<sup>50</sup> Thus, employers and health insurers cannot legally seek genetic data, including family health histories about individuals.<sup>51</sup> They also cannot lawfully make adverse decisions based on findings of genetic abnormalities or family histories that indicate susceptibility to diseases that could manifest later in life.<sup>52</sup> However, GINA's sole focus is genetic information, and it does not reach any other predictive data.

Other laws also forbid disability-based discrimination. For example, the Rehabilitation Act of 1973 prohibits federal sector employers and “any program receiving federal financial assistance” from discriminating against individuals because of their disabilities.<sup>53</sup> Such programs include colleges and universities that receive direct federal financial assistance or even indirect assistance in the form of federal financial aid for their students.<sup>54</sup> Almost all states have also adopted statutory anti-discrimination in employment mandates that include disability as a protected classification.<sup>55</sup>

The definition of “individual with a disability” in these laws, however, is generally similar to the ADA's definition of the term. No law covers individuals who are currently healthy but are regarded as being vulnerable to illness in the future.<sup>56</sup>

## V. RECOMMENDATIONS

The ADA and other disability rights laws should be amended to respond to emerging discrimination threats in the era of big data. Specifically, the laws should account for the

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<sup>50</sup> Genetic Information Non-Discrimination Act, Pub. L. No. 110-233, 122 Stat. 881 §§ 201(4) & 202(a) (2008); 29 U.S.C. § 1182 (2010); 42 U.S.C. § 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. 42 U.S.C. §§ 2000ff(4)(A) (2010).

<sup>51</sup> 29 U.S.C. § 1182 (c) & (d) (2010); 42 U.S.C. § 2000ff-1(b) (2010).

<sup>52</sup> 29 U.S.C. § 1182 (a) & (b) (2010); 42 U.S.C. § 2000ff-1(a) (2010).

<sup>53</sup> 29 U.S.C. §§ 791 and 794(a) (2010).

<sup>54</sup> Disability Rights California, Rights of Students with Disabilities in Higher Education, July 2013, available at <http://www.disabilityrightsca.org/pubs/530901.pdf>.

<sup>55</sup> National Conference of State Legislatures, State Laws on Employment-Related Discrimination, July 2015, <http://www.ncsl.org/documents/employ/Discrimination-Chart-2015.pdf>.

<sup>56</sup> 29 U.S.C. § 705(20)(B) (2010) (referring to the ADA's definition); Georgetown Law, Chart Comparing State Definitions of Disability, last visited October 20, 2016, <https://www.law.georgetown.edu/archiveada/documents/statebystatechart--updated.pdf>; see e.g. Ohio Rev. Code Ann. § 4112.01 (West) (defining “disability” as “a physical or mental impairment that substantially limits one or more major life activities, including the functions of caring for one's self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working; a record of a physical or mental impairment; or being regarded as having a physical or mental impairment”).

likelihood that third parties will obtain information that will enable them to make predictions about data subjects' future health status and to discriminate based on these data. For the sake of brevity I will focus on the Americans with Disabilities Act in this section, but all anti-discrimination laws could follow the model I propose.

### **A. Expanding the “Regarded as” Provision**

The easiest fix would be to amend the ADA’s “regarded as” provision.<sup>57</sup> The provision should be broadened to cover individuals who are perceived as likely to develop physical or mental impairments in the future. Thus, the law would reach not only people who are considered to be currently impaired, but also those who are thought to be at risk of impairment in later years based on information about their habits, purchases, biomarkers, or other indicators. As is generally true in “regarded as” cases, a plaintiff should not have to establish that the decision-maker believed she would develop a condition that rises to the level of a disability. Instead, plaintiffs should have to prove only that decision-makers were worried about future non-transitory physical or mental impairments.<sup>58</sup>

Opponents might object that the proposed change would expand the ADA to reach all Americans rather than to protect a “discrete and insular minority.”<sup>59</sup> One of the traditional justifications for the anti-discrimination laws is that they cover only specific, well-defined vulnerable populations, and extending coverage to any worker who might be subject to data mining would be a departure from this approach. In truth, however, the ADA’s 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>60</sup> Thus, Congress did not intend the ADA’s target population to be narrow in scope.

Moreover, the ADA’s broad coverage would be consistent with that of many other federal anti-discrimination laws.<sup>61</sup> Title VII of the Civil Rights Act of 1964 covers anyone who suffers discrimination based on race, color, religion, sex, or national origin, including males and Whites.<sup>62</sup> The Equal Pay Act prohibits sex-based wage discrimination against both men and women.<sup>63</sup> Likewise, GINA protects all individuals against discrimination based on genetic information.<sup>64</sup> This includes individuals who are perfectly healthy but who are believed to be at risk of future ailments because of genetic abnormalities. Thus, GINA already embraces the

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<sup>57</sup> 42 U.S.C. §§ 12102(1)(C) and (3) (2010).

<sup>58</sup> See supra note 47 and accompanying text.

<sup>59</sup> See Sharona Hoffman, *The Importance of Immutability*, 52 *William & Mary Law Review* 1483, 1500-04 (2011) (critiquing the theory that the employment discrimination laws are designed to protect discrete and insular minorities).

<sup>60</sup> See supra, notes 47-48 and accompanying text.

<sup>61</sup> The only federal anti-discrimination 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. 29 U.S.C. § 631(a) (2010).

<sup>62</sup> 42 U.S.C. § 2000e-2 (2010).

<sup>63</sup> 29 U.S.C. § 206(d)(1) (2010).

<sup>64</sup> 42 U.S.C. § 2000ff-4(a) (2010).

approach that I propose in this chapter, and the suggested ADA modification would bring the two statutes into better alignment.

Expanding the “regarded as” prong of the ADA’s definition of “disability” is also consistent with the statute’s central mission. The ADA declares that its purpose is “to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities.”<sup>65</sup> Moreover, the “regarded as” provision intends to combat “myths, fears, and stereotypes associated with disabilities.”<sup>66</sup> The law was enacted in 1990, long before the emergence of the big data phenomenon. Today, individuals’ health vulnerabilities can increasingly be detected before their disabilities become apparent, and discrimination based on predictive data is just as pernicious as discrimination based on existing symptoms. Data analysis practices that enable health status projections can fuel and exacerbate “myths, fears, and stereotypes” about disabilities. Consequently, extending the ADA’s reach is both logical and necessary.

## **B. Disclosing Data Mining Practices**

Standing alone, language prohibiting discrimination based on predictions of future impairments may not provide adequate protection. This is because data subjects may never discover that employers, lenders, educators, or anyone else used data mining or data broker services to collect predictive information about them and therefore will have no evidence with which to establish discrimination cases.

In order to provide meaningful protection, the ADA will need to include disclosure requirements for big data use. Title I of the ADA has a section that governs how and when employers can obtain medical information about workers.<sup>67</sup> The provision should be revised to instruct employers that they must inform applicants and employees in writing if they intend to obtain health-related data about them by any means other than traditional medical exams and inquiries. In Title III a similar disclosure requirement could be added after the statement that discrimination includes “the imposition or application of eligibility criteria that screen out or tend to screen out an individual with a disability.”<sup>68</sup> Title II of the ADA would require the addition of a separate provision to address the use of predictive data or should reference the provision in another title.

## **VI. Conclusion**

In today’s data-driven world, employers, lenders, marketers, educators, and many others are able to obtain a bounty of health-related information about individuals. These parties may then use data to identify those with future health risks and make adverse decisions concerning them.

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<sup>65</sup> 42 U.S.C. § 12101(b)(1) (2010).

<sup>66</sup> Risa M. Mish, “Regarded as Disabled” Claims under the ADA: Safety Net or Catch-All?

1 University of Pennsylvania Journal of Labor and Employment Law 159, 160 (1998), quoting *School Bd. of Nassau County v. Arline*, 480 U.S. 273, 279 (1987) (discussing the Rehabilitation Act’s “regarded as” provision).

<sup>67</sup> 42 U.S.C. § 12112(d) (2010).

<sup>68</sup> 42 U.S.C. § 12182(b)(2)(A)(i) (2010).

This chapter has argued that legislators must respond to the availability of new data tools. It does not suggest that the use of big data be banned altogether. Instead, legislators should amend the ADA (and other anti-discrimination laws) to prohibit discrimination based on predictive health information and to require disclosure of big data use to data subjects.

These requirements should not open the floodgates of litigation. In order to prevail, plaintiffs would need to show that 1) decision-makers engaged in data mining or sought information from data brokers; 2) they discovered health-predictive information; and 3) they based an adverse decision on those data. Doing so may prove extremely difficult if not impossible for many plaintiffs. Therefore, attorneys are not likely to pursue weak cases.

The great hope of the anti-discrimination statutes is that the vast majority of covered entities are law-abiding and will voluntarily comply with regulatory mandates. The proposed approach aligns the law with new technology and provides the public with much-needed protection.