

Comment

The Privacy of Your Genetic Data: Must Anti-Discrimination Laws be Genetic or Generic?*

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I. Introduction

CURRENT UNITED STATES LAWS surrounding the privacy of genetic information are insufficient to protect individuals from the misuse of their genetic data for discriminatory purposes. As of March 15, 2018, more than five million people have paid ninety-nine dollars each to spit into the DNA testing service 23andMe's mail-order tubes.¹ This information is collected, tested, and compared with the DNA from individuals around the world to provide customers their Ancestry Composition.² 23andMe retains genetic data as reference for future customers' genetic testing. Ancestry.com—another DNA testing service—currently has three million paying subscribers and has performed DNA testing for over ten million people.³ Ancestry.com contains over twenty billion family history records, the largest online collection in the world.⁴ These records include sensitive information about births, marriages, deaths, military service, and immigration,

* Deborah Hellman, *What Makes Genetic Discrimination Exceptional?*, 29 AM. J.L. & MED. 77, 78 (2003).

1. Chloe Cornish, *23andMe: The Genomic Test of Time*, FIN. TIMES, Mar. 15, 2018, <https://www.ft.com/content/098008c0-ff9c-11e7-9e12-af73e8db3c71> [<https://perma.cc/KT5E-GCPJ>].

2. *How 23andMe Personal Genetic Service Works*, 23ANDME, <https://customer.care.23andme.com/hc/en-us/articles/227968028-How-23andMe-works> [<https://perma.cc/6G5A-UWWM>].

3. *Ancestry Company Facts*, ANCESTRY, <https://www.ancestry.com/corporate/about-ancestry/company-facts> [<https://perma.cc/JNP5-RWGZ>].

4. *Id.*

among others.⁵ One can access the vital records of their ancestors by requesting them from an index.⁶

Just fifty years ago, no one would have thought genetic testing would be as commonplace as it is today. It was nearly unfathomable that an individual could discover their own genetic composition in the privacy of their own home. However, this information may not be as private you think.

This Comment will explore the potential discriminatory effects of genetic data collection and how those consequences can be avoided. Part I introduces the concept of genetic information. Part II highlights some of the benefits of genetic information testing services, explains why they are outweighed by privacy concerns, and examines how the government treats other types of private information. Part III introduces the Genetic Information Nondiscrimination Act (“GINA”), the act Congress passed to combat the potential misuse of genetic information. Parts IV and V identify specific risks in collecting genetic information in the context of professional sports and public schools by highlighting similarities with discrimination cases under the Americans with Disabilities Act (“ADA”). It also addresses state law deficiencies in protecting genetic information in public schools. Part VI discusses further consequences of collecting genetic information on a national scale. Part VII discusses potential new regulations to address these problems. Part VIII concludes by urging for the adoption of stricter laws surrounding the use of genetic information by amending GINA to expand the scope of its protection.

II. Background on Genetic Information

Genetic information is defined as an individual’s genetic tests, the genetic tests of an individual’s family members, the manifestation of a disease or disorder in an individual’s family members, or any request for or receipt of genetic services (or participation in clinical research that includes genetic services) by an individual or any of the individual’s family members.⁷ Genetic services include genetic tests, genetic counseling, and genetic education.⁸ A genetic test is “an analysis of human DNA, RNA, chromosomes, proteins, or metabolites that

5. *Id.*

6. *Vital Records: Birth, Marriage, Death*, ANCESTRY, <https://www.ancestry.com/search/categories/34/> [<https://perma.cc/8CB2-HPDF>].

7. *Ancestry Composition*, 23ANDME, <https://www.23andme.com/ancestry-composition-guide/> [<https://perma.cc/MPR6-9SSX>].

8. *Id.*

detects genotypes, mutations, or chromosomal changes.”⁹ 23andMe and Ancestry.com provide such genetic tests.

A. Benefits of Genetic Information

Admittedly, there are many benefits to genetic information services. Genetic tests have become more prevalent since the Human Genome Project¹⁰ mapped out the entire DNA sequence in the human genome, resulting in a surge in genetic research and the development of technology.¹¹ Genetic tests inspect an individual’s genes to determine whether the individual has a genetic condition or disease, or whether that individual is predisposed to future disease.¹² Today, genetic testing is available for over 2000 rare and common conditions from over 500 laboratories.¹³ Some examples of genetic tests that are available today include diagnostic testing, predictive and pre-symptomatic genetic testing, carrier testing, prenatal testing, pre-implantation genetic testing, newborn screening, pharmacogenetic testing, and research genetic testing.¹⁴ These types of tests are increasingly widespread due to increased availability,¹⁵ and as a consequence, more people are taking these tests.¹⁶

There are various medical conditions that have been traced directly to defective genes, as well as many other conditions that have suspected genetic factors, including: “Huntington’s chorea, cystic fibrosis, Alzheimer’s disease, sickle cell anemia, thalassemia, cancer, heart disease, muscular dystrophy, diabetes, arthritis, dyslexia, and some mental illnesses.”¹⁷ Scientists are also able to create more effective treatment programs by using the results of genetic testing to predict how an individual will respond to a particular drug.¹⁸ Furthermore, early detection and treatment of medical disorders is

9. *Id.*

10. *The Human Genome Project*, NAT’L HUM. GENOME RES. INSTITUTE, <https://www.genome.gov/human-genome-project> [<https://perma.cc/NH5V-429T>].

11. Ashley M. Ellis, *Genetic Justice: Discrimination By Employers and Insurance Companies Based on Predictive Information*, 34 TEX. TECH. L. REV. 1071, 1075 (2003).

12. *Id.* at 1075.

13. NAT’L INSTS. OF HEALTH, FACT SHEET - GENETIC TESTING: HOW IT IS USED FOR HEALTHCARE I, 1 (2010), [https://report.nih.gov/NIHfactsheets/Pdfs/GeneticTesting-HowItIsUsedForHealthcare\(NHGRI\).pdf](https://report.nih.gov/NIHfactsheets/Pdfs/GeneticTesting-HowItIsUsedForHealthcare(NHGRI).pdf) [<https://perma.cc/UL28-GKVJ>].

14. *Id.*

15. *Id.*

16. Antonio Regalado, *2017 Was the Year Consumer DNA Testing Blew Up*, MIT TECH. REV. (Feb. 12, 2018), <https://www.technologyreview.com/s/610233/2017-was-the-year-consumer-dna-testing-blew-up/> [<https://perma.cc/5G4Y-KR64>].

17. Ellis, *supra* note 11, at 1075.

18. *Id.*

now possible since genetic testing provides information about an individual's predisposition to a disease before symptoms even appear.¹⁹ For example, when Angelina Jolie received the results of a genetic test indicating that she had an extremely high risk of developing breast cancer, she underwent a preventative double mastectomy.²⁰ This is just one example of how genetic testing can help to empower individuals to make more informed healthcare decisions.

B. The Benefits of Genetic Information Do Not Outweigh the Privacy Concerns

The benefits of genetic testing still are not enough to countervail the privacy implications of using genetic information. Genetic information is different from other types of personal information, such as medical information, in numerous ways.

First, genetic information could “support conclusions about an individual that would have been impossible to reach before.”²¹ For example, scientists have recently discovered a group of “violent genes” that have been shown to contribute to severe behaviors such as homicide.²² However, many of these conclusions “supported” by the genetic information are not actually conclusions and instead only show a propensity or increased likelihood of contracting a particular condition or behaving a certain way. Furthermore, even if a genetic test accurately predicts susceptibility to a condition, the test “will not indicate when the individual will develop symptoms, or how severe the symptoms will be.”²³ Although establishing a link between an individual's genetic makeup and propensity to disease may lead to better treatment, many worry that obtaining this information may also lead to discrimination.²⁴ For some, this information could inhibit access to health insurance, life insurance, and disability insurance, as well as in other contexts such as employment, child custody decisions, or adoption.²⁵ For instance, if a health insurer has the knowledge that an indi-

19. *Id.*

20. Jennifer Melton, *What's in Your DNA?*, 20 NO. 2 ARIZ. EMP. L. LETTER 3 (2013).

21. WILLIAM MCGEVERAN, *PRIVACY AND DATA PROTECTION LAW 787* (Robert C. Clark et al. eds., 2016).

22. Dolores Garcia-Arocena, *The Genetics of Violent Behavior*, JACKSON LABORATORY, <https://www.jax.org/news-and-insights/jax-blog/2015/december/the-genetics-of-violent-behavior> [<https://perma.cc/HX89-5LX5>].

23. *Genetic Discrimination in the Workplace Factsheet*, ACLU, <https://www.aclu.org/other/genetic-discrimination-workplace-factsheet> [<https://perma.cc/A8J5-VGLX>].

24. Deborah Hellman, *What Makes Genetic Discrimination Exceptional?*, in *GENETICS AND GENE THERAPY*, 77, 77 (Sheila A.M. McLean ed., 2005).

25. *Id.*

vidual possesses a gene that is linked to a certain disease, the insurer may raise that individual's deductible to a price the individual cannot afford.

Second, this sphere is highly unpredictable as the technology is still very new, and there may be social implications that we have not yet fathomed. As Justice Kennedy stated in *Maryland v. King*,²⁶ "The advent of DNA technology is one of the most significant scientific advancements of our era. The full potential for use of genetic markers in medicine and science is still being explored, but the utility of DNA identification in the criminal justice system is already undisputed."²⁷ The National Institute of Health warned, "as we gain more knowledge in this particular area, and begin to understand the relationship between genes and personal characteristics,"²⁸ there is a high likelihood that a specific piece of DNA will provide even more information about an individual than it does currently.²⁹ For example, we may discover that a particular gene pattern increases the likelihood of anti-social behavior or makes certain individuals more prone to commit crimes.³⁰ DNA that has already been collected for present purposes may be used to try to preempt these future behaviors and actions.

Third, each person's genetic code is extremely individualized and each data point is unique in that it is only associated with one person in the world, unless you are an identical twin.³¹ The human genome is made up of three billion base pairs, and in merely 0.1% of the human genome (or three million base pairs) lies the differences in each of us, including differences in hair color, eye color, height, risk of obesity and heart disease, whether you are lactose intolerant, or how fast you can run.³² Moreover, this 0.1% variation can happen anywhere in our genome,³³ making each person's genetic code singularly identifiable.

26. *Maryland v. King*, 569 U.S. 435 (2013).

27. *Id.* at 442.

28. NAT'L INST. OF HEALTH, NIH CURRICULUM SUPPLEMENT SERIES [INTERNET] (2007), <https://www.ncbi.nlm.nih.gov/books/NBK20363/> [<https://perma.cc/3TNE-XBGH>].

29. BOARD ON HEALTH SCIENCES Policy, THE NAT'L ACAD., GENES, BEHAVIOR, AND THE SOCIAL ENVIRONMENT: MOVING BEYOND THE NATURE/NURTURE DEBATE, 50 (Hernandez LM & Blazer DG, 2006).

30. Laura A. Baker, Serena Bezdjian & Adrian Raine, *Behavioral Genetics: The Science of Antisocial Behavior*, 16 LAW & CONTEMP. PROBLEMS, 7 (2006).

31. *What Makes You Unique*, SCIENCE SHORTS (Dec. 31, 2016), <http://www.science shorts.com/what-makes-you-unique/> [<https://perma.cc/P8EU-3VR8>].

32. Sharon Briggs, *Genetics Has Proven That You're Unique—Just Like Everyone Else*, QUARTZ (Mar. 21, 2017), <https://qz.com/936525/personal-dna-testing-and-genetic-scientists-are-proving-that-youre-unique-just-like-everyone-else/> [<https://perma.cc/9DJR-PCRH>].

33. *Id.*

This means that an individual's genetic code should be afforded more protection than any other personally identifying information, including a social security number.

Fourth, genetic data not only reflects information about the data subject, but also the data subject's blood relatives.³⁴ This means that individuals who have never consented to the disclosure of their genetic information and may not even be aware of its disclosure may be implicated.

Finally, because our understanding of genetics is still in its infancy stage, it "disrupts settled models for thinking about privacy."³⁵ For example, a recent study revealed that many individuals conflate privacy with confidentiality, control, and security.³⁶ However, in the study many also felt the benefits of the information gained from genetic tests were more important than protecting privacy.³⁷ Also, "[m]ost healthcare providers do not have training in genetics analysis, and many who order genetic tests may not know how to interpret the results."³⁸ This discrepancy shows there is still much confusion surrounding genetic privacy. Genetic privacy should be given the utmost protection at least until it is better understood, and people are able to make more informed decisions about it.

C. How the Supreme Court Has Treated Other Kinds of Private Information

The Supreme Court's treatment of other kinds of private information helps define how newly obtained genetic information should be treated in the legal sphere. Although genetic information privacy is a relatively new concept, there are many related "zones of privacy"³⁹ issues surrounding medical information and digital information that society has dealt with in the past and that overlap with this newer idea of privacy.

34. U.C. BERKELEY COMM. FOR PROTECTION OF HUMAN SUBJECTS, GENETIC/GENOMIC RESEARCH 2 (2017), https://cphs.berkeley.edu/genetic_genomic.pdf [<https://perma.cc/28WH-2H4A>].

35. McGEVERAN, *supra* note 21, at 788.

36. Ellen W. Clayton, *Review Reveals Ambiguous Understanding of Genetic Privacy in US Study Participants*, SCIENCE DAILY (Oct. 31, 2018), <https://www.sciencedaily.com/releases/2018/10/181031141429.htm> [<https://perma.cc/TP6C-S5D4>].

37. *Id.*

38. *Genetic Discrimination in the Workplace Factsheet*, *supra* note 23.

39. *Griswold v. Connecticut*, 381 U.S. 479, 484 (1965).

The famous case *Whalen v. Roe*⁴⁰ sheds some light on medical information privacy. In this case, the State of New York passed the New York State Controlled Substances Act, which classified potentially harmful drugs into five schedules.⁴¹ This Act required physicians to use an official form to prescribe Schedule II drugs—dangerous drugs that also have a recognized medical use.⁴² A copy of this form was then sent to the State Department of Health where it was securely stored for five years.⁴³ The issue was whether this record-keeping violated the constitutional right to privacy as a liberty interest under the Fourteenth Amendment.⁴⁴ Appellees argued that “the mere existence in readily available form of the information about patients’ use of Schedule II drugs create[d] a genuine concern that the information [would] become publicly known and that it [would] adversely affect their reputations.”⁴⁵ However, the Court held that the State of New York’s interest in the recording and storage of appellee’s medical information, including appellee’s use and prescription of Schedule II drugs, outweighed any individual privacy concerns because the purpose of the collection was to prevent the abuse of these drugs in the unlawful market.⁴⁶ Moreover, there was a low risk of potential abuse of data accumulation and disclosure in light of the many protections surrounding the information in the department of health.⁴⁷

The Supreme Court in *Riley v. California*⁴⁸ discussed the issue of digital information privacy. Here, police pulled over Riley because he was driving with a suspended license, impounded his car, and ran an inventory search in the process.⁴⁹ When the police found two firearms in the car, they arrested Riley for possession.⁵⁰ Riley had his cell phone in his pocket when he was arrested, so a detective examined photographs and videos on his phone for evidence of gang-related activity.⁵¹ Police used this evidence to tie Riley to a gang-related shooting a few weeks earlier.⁵² The information gathered from his cell

40. *Whalen v. Roe*, 429 U.S. 589 (1977).

41. *Id.* at 592.

42. *Id.* at 593.

43. *Id.*

44. *Id.* at 602.

45. *Id.* at 600.

46. *Id.* at 597–98.

47. *Id.* at 601–02.

48. *Riley v. California*, 573 U.S. 373 (2014).

49. *Id.* at 378.

50. *Id.*

51. *Id.* at 378–79.

52. *Id.* at 379.

phone was used to convict him at trial.⁵³ However, the Supreme Court reversed this conviction, holding that police may not, without a warrant, search digital information on a cell phone seized from an individual who has been arrested.⁵⁴ The Court's conclusion was based on the immense storage capacity of a cell phone, which allowed a police officer to learn many more intrusive details about a person's life than searching other objects such as physical papers.⁵⁵ This cell phone search was a violation of Riley's Fourth Amendment right to privacy.⁵⁶

As seen with both *Whalen* and *Riley*, it is clear that the right to privacy is woven throughout the Constitution, and there is an inherent right to privacy in both the Fourteenth and Fourth Amendments.⁵⁷ In *Whalen*, the Court found that the medical information did not need more protection because it was already stored securely with limited access and use for a finite amount of time, and because it involved a legitimate governmental interest.⁵⁸ However, genetic information is distinguishable from the medical information in *Whalen* because, although there may be a similar governmental interest in terms of identifying medical conditions or preventing crime, there are not enough safeguards surrounding it (even with GINA discussed below) to limit government access as well as access by private entities. In *Riley*, the Court found that a cell phone's vast storage potential of personal information warranted it more protection than other searched items.⁵⁹ Similarly here, the data contained in the cell phone parallels the scope of information which can be obtained through genetic testing and its high potential for abuse, which is why it warrants the highest level of protection under the law.

III. Congress's Incomplete Response to Genetic Discrimination Concerns: GINA

In May 2008, the United States Congress passed the Genetic Information Nondiscrimination Act.⁶⁰ GINA was unusually progressive because it protected against a form of discrimination that was not yet

53. *Id.* at 379–80.

54. *Id.* at 403.

55. *Id.*

56. *Id.*

57. *See id.*; *Whalen v. Roe*, 429 U.S. 589 (1977).

58. *Whalen*, 429 U.S. at 589.

59. *Riley*, 573 U.S. at 393–94.

60. 42 U.S.C. §§ 2000ff et. seq. (2012).

common.⁶¹ Congress enacted GINA in anticipation of a future in which genetic testing would be widespread and inexpensive, making the danger of genetic discrimination very real.⁶² Congress's purpose was to "address public concerns over the potential loss of health coverage or employment resulting from insurers and employers having access to individuals' genetic information."⁶³ In answering these concerns, "GINA generally prohibits discrimination based on genetic information and restricts the acquisition and disclosure of genetic information."⁶⁴

Title I of GINA prohibits group health plans and insurers from: (1) increasing group premium or contribution amounts based on genetic information; (2) requesting or requiring individuals or family members to undergo a genetic test; (3) requesting, requiring, or purchasing genetic information before or in connection with enrollment; or (4) requesting, requiring, or purchasing genetic information at any time for underwriting purposes,⁶⁵ i.e., using the information to calculate the level of risk involved and determining an insurance rate based on that information. However, Title I is specifically limited to not-yet-manifested conditions.⁶⁶ Although a genetic test means an analysis of human DNA, RNA, chromosomes, proteins, or metabolites for the detection of genotypes, mutations, or chromosomal changes, it does not include an analysis of proteins or metabolites that are directly related to a manifested disease, disorder, or pathological condition.⁶⁷ This means that if an individual discovers a disease, disorder, or pathological condition for which a health care professional could also reasonably diagnose the individual for, this information would not be covered by GINA. In other words, GINA only applies under the limited circumstance of an individual carrying a gene related to a disease, but not actually showing symptoms for that disease, which drastically narrows the scope of coverage GINA provides.

61. Sarah Zhang, *The Loopholes in the Law Prohibiting Genetic Discrimination*, ATLANTIC (Mar. 13, 2017), <https://www.theatlantic.com/health/archive/2017/03/genetic-discrimination-law-gina/519216/> [https://perma.cc/7DNH-LZ52].

62. Mark A. Rothstein, *GINA's Beauty is Only Skin Deep*, COUNCIL FOR RESPONSIBLE GENETICS, <http://www.councilforresponsiblegenetics.org/genewatch/GeneWatchPage.aspx?pageId=184&archive=yes> [https://perma.cc/2FYP-3ZCJ].

63. Practical Law Emp. Benefits & Exec. Comp., GINA Compliance for Health and Welfare Plans, Practical Law Practice Note 5-521-7266 (Thompson Reuters 2019).

64. *Id.*

65. *Id.*

66. *See generally, id.* (discussing the various coverage and limitation under Article I of GINA).

67. 29 C.F.R. § 2590.702-1(a)(5)(i) (2019).

Title II of GINA: (1) prohibits the use of genetic information in employment decision making; (2) prohibits harassment of an applicant or employee based on the employee's genetic information; (3) prohibits retaliation against an applicant or employee for filing a discrimination charge, participating in a discrimination proceeding, or otherwise opposing discrimination; (4) generally restricts employers and other covered entities under GINA Title II from requesting, requiring, or purchasing genetic information, unless one or more of six narrow exceptions apply; (5) requires genetic information to be maintained as a confidential medical record; (6) imposes limits on the disclosure of genetic information; and (7) provides remedies for individuals whose genetic information is acquired, used, or disclosed in violation of GINA Title II.⁶⁸ However, an employer is not liable for violating this provision if "the employer obtained the information inadvertently."⁶⁹ Therefore, "if a manager or supervisor accidentally overhears a conversation about genetic information or learns of genetic information through a casual conversation with the employee" or discovers the genetic information through a social media site, then the employer is free to use the learned information.⁷⁰ Also, a covered entity may disclose genetic information in some circumstances, including notifying a federal, state, or local public health agency if the situation concerns a contagious disease that presents an imminent hazard of death or life-threatening illness.⁷¹

GINA, although ahead of its time, is still insufficient to protect the privacy interests associated with genetic information. Although the Act defines discrimination separately under each title and shows what it would look like in the context of both health insurers and employers, it does not include disparate impact claims. In the workplace context, similar to Title VII of the Civil Rights Act of 1964, "GINA addresses adverse treatment in hiring, discharging, or otherwise discriminating in employment matters based upon genetic information."⁷² However, disparate impact claims are not included: "[S]eemingly neutral practices that have a disproportionate impact on

68. Practical Law Emp. Benefits & Exec. Comp., *supra* note 63.

69. Stephen E. Trimoli & Marissa Becker Ruggiero, *Navigating the Genetic Information Nondiscrimination Act of 2008*, FED. LAW., Nov./Dec. 2011, at 24, 25.

70. DEBRA S. FRIEDMAN, TITLE II OF THE GENETIC INFORMATION NONDISCRIMINATION ACT OF 2008 *3-4 (2012), 2012 WL 191178.

71. 29 C.F.R. § 1635.9(b)(6) (2019).

72. Brad Reid, *A Brief Legal Overview of the Genetic Information Nondiscrimination Act*, HUFFPOST (May 12, 2016, 01:55 PM ET), https://www.huffingtonpost.com/brad-reid/a-brief-legal-overview-of_b_9934270.html [<https://perma.cc/GE59-TUCE>].

a protected group are not included in GINA.”⁷³ Furthermore, GINA contains the above loopholes that allow both health insurers and employers to gain access to and potentially misuse an individual’s genetic information.⁷⁴ Finally, GINA only applies to health insurers and employers and is deficient in preventing genetic discrimination in many other contexts.⁷⁵ For example, it has no provision that applies to professional sports. Major League Baseball (“MLB”) “currently collects DNA samples from prospective players whose identity it is questioning in order to prevent age fraud.”⁷⁶ Although GINA bars employers from using genetic data in workplace decisions, it is possible that the Equal Employment Opportunity Commission (“EEOC”), as the federal agency responsible for promulgating regulations concerning GINA, could determine that “neither age nor identity represent ‘genotypes, mutations, or chromosomal changes’ which might be enough to exclude the testing from GINA’s definition.”⁷⁷ GINA also has no provision that applies to public entities such as public schools,⁷⁸ an especially clear shortcoming when compared to the comprehensive Americans with Disabilities Act (“ADA”), which prevents disability discrimination in public schools under its Title II.⁷⁹

IV. Professional Sports: Specific Risks Involved in Collecting Genetic Information

GINA was enacted to protect the blue-collar railroad worker, but there are many other industries such as professional sports that have not yet felt its effects.⁸⁰ Professional sports pose “a unique opportunity for exploitation of genetic information since athletic ability and physical health often determine employment decisions.”⁸¹ Genetic testing

73. *Id.*

74. Zhang, *supra* note 61.

75. *Genetic Discrimination*, NAT’L HUM. GENOME RES. INSTITUTE, <https://www.genome.gov/about-genomics/policy-issues/Genetic-Discrimination> [<https://perma.cc/PJ3Q-J822>].

76. Doyle Slifer, *Implications of the Genetic Information Nondiscrimination Act (GINA) on Professional Sports*, ILL. BUS. L. J. (Nov. 3, 2009), <https://publish.illinois.edu/illinoisblj/2009/11/03/implications-of-the-genetic-information-nondiscrimination-act-gina-on-professional-sports/> [<https://perma.cc/U7KZ-AVGS>].

77. *Id.*

78. Zhang, *supra* note 61.

79. 42 U.S.C. §§ 12131 et. seq. (2012).

80. Jesse A. Bland, Note, *There Will be Blood. . . Testing: The Intersection of Professional Sports and the Genetic Information Nondiscrimination Act of 2008*, 13 VAND. J. ENT. & TECH. L. 357, 380 (2011).

81. *Id.* at 369.

in sports has great potential for abuse after an athlete's genetic data is collected for legitimate purposes.

As previously discussed, the term "genetic information" does not incorporate "information about the sex or age of any individual."⁸² This means that professional sports organizations can use the pretext of testing for age to actually test for genetic diseases and disorders. Professional athletes are still employees under GINA, and they deserve full protection from genetic testing, not just the incomplete protection that GINA currently provides them.

Genetic information as a gateway to discrimination has already been experienced in the cases of Miguel Sano and Eddy Curry. Miguel, a sixteen-year-old MLB prospect from the Dominican Republic, underwent DNA testing to confirm his age.⁸³ Miguel's team can use his DNA to confirm not just his age, but also "his susceptibility to genetic diseases or disorders,"⁸⁴ which can be used to predict his medical future, and therefore, what the team would pay him.⁸⁵ Eddy is a former National Basketball Association ("NBA") player whose team had demanded he take a DNA test as a condition for renewing his contract.⁸⁶ After Eddy experienced heart discomfort during the 2005 season, doctors diagnosed him "with a benign case of 'athlete's heart,' yet the Chicago Bulls kept him off the court for the remainder of the season."⁸⁷ The Bulls insisted on a DNA test during contract negotiations due to their worry that his condition would increase the chance of a fatal heart attack while playing for the team.⁸⁸ Although Eddy never submitted to the test, if he had, his team could have used this information to lower his pay based on the results.

These two examples show the gateway for potential misuse of genetic information in sports. GINA "presumably bars genetic testing in professional sports [only] to the extent that test results must not factor into employment decisions,"⁸⁹ leaving many loopholes in the professional sports arena.

There may be a risk in the future that entry into the world of professional sports will be restricted to a portion of the population who happen to have a specific genetic makeup. Although these

82. *Id.* at 374.

83. *Id.* at 358.

84. *Id.* at 359.

85. *Id.*

86. *Id.*

87. *Id.* at 358-59.

88. *Id.* at 359.

89. *Id.* at 359-60.

problems have not yet fully manifested in professional sports, genetic testing in sports has great potential for abuse without further laws in place to limit the use of an athlete's genetic data once it is collected for legitimate purposes.

V. Public Schools: Specific Risks Involved in Collecting Genetic Information

Similar issues are present in public schools. *Chadam v. Palo Alto Unified School District*,⁹⁰ currently pending remand in a California district court, sheds some light on the issue of how genetic information might be used to discriminate against students in public schools. Here, Colman Chadam underwent genetic screening following cardiac surgery as a newborn.⁹¹ The screening indicated that he had genetic markers for cystic fibrosis ("CF"), but further testing revealed that he did not actually have CF.⁹²

Chadam's mother later enrolled him in a middle school in the Palo Alto Unified School District ("PAUSD").⁹³ In the enrollment process, his mother had to submit several medical forms, including a "Report of Health Examination for School Entry," detailing "personal and privileged medical information."⁹⁴ In this form, "his parents disclosed that their son was a carrier for cystic fibrosis meaning he had one mutated copy and one normal copy of the gene that causes cystic fibrosis but did not exhibit any symptoms of the disease."⁹⁵

Chadam began attending Jordan Middle School on August 16, 2012.⁹⁶ On August 22, 2012, one of Chadam's teachers contacted his parents regarding his medical condition.⁹⁷ On September 11, 2012, one of Chadam's teachers inaccurately disclosed that Chadam had CF to the parents of another student attending the middle school during a parent-teacher meeting without permission from the Chadams.⁹⁸ Later that day, PAUSD arranged a meeting with the Chadams, the middle school principal, a school nurse, and the vice principal of the

90. *Chadam v. Palo Alto Unified School District*, 666 F. App'x 615 (9th Cir. 2016).

91. *Chadam v. Palo Alto Unified School District*, 2014 WL 5694080, at *1 (N.D. Cal. 2014).

92. *Id.*

93. *Id.*

94. *Id.*

95. Michael R. Dohn, Article, *Personal Genomics and Genetic Discrimination: Is Increased Access a Good Thing?*, 45 W. ST. J. REV. 107, 129 (2018).

96. *Chadam*, 2014 WL 5694080, at *1.

97. *Id.*

98. *Id.*

sixth grade.⁹⁹ At the meeting, the Chadams were informed that the children of the parent from the parent-teacher meeting both had active CF, and that the parents had “discovered” Chadam’s condition.¹⁰⁰ These parents wanted Chadam to attend a different school because they were worried that Chadam and the children with CF posed cross-threats to each other.¹⁰¹ This is because “[p]eople with CF are not supposed to be around each other because they can easily transmit to and contract from each other a certain kind of bacteria that CF causes them to carry in their lungs.”¹⁰² Chadam’s parents then informed the other meeting members that Chadam did not actually have CF.¹⁰³

On September 13, 2012, a doctor sent a letter to PAUSD concerning the medical issues raised by Chadam’s presence at Jordan Middle School and recommending that Chadam be removed from the school for the safety of the other two children with CF.¹⁰⁴ After much back and forth between Chadam’s parents, the parents of the students with CF, the school officials, and the doctor, the Chadams were told on September 17, 2012 that, based on the demands of the parents of the students with CF and in light of Chadam’s private medical information, Chadam had to be sent to another middle school.¹⁰⁵

On September 20, 2012, the Chadams provided a letter to the school from another doctor who stated that Chadam did not have any signs of CF, and that he did not think that “this boy is any risk whatsoever to other children with [cystic fibrosis] even if they were using the same classroom.”¹⁰⁶ The Chadams confronted the school officials again the same day and the officials told them that the decision to remove Chadam from the school was based on a letter from a Stanford doctor.¹⁰⁷ Even though Chadam’s mother tried multiple times to provide more evidence that Chadam was not at risk to any other child, Chadam was removed from Jordan Middle School on October 10, 2012.¹⁰⁸

On October 12, 2012, the Chadams brought suit in a California state court seeking to enjoin PAUSD from transferring Chadam to an-

99. *Id.*

100. *Id.*

101. *Id.* at *2.

102. Tyler Wood, Comment, *Genetic Discrimination in Public Schools: A Common-Sense Exception*, 49 U. PAC. L. REV. 309, 320 (2018).

103. *Chadam*, 2014 WL 5694080, at *1.

104. *Id.*

105. *Id.* at 2.

106. *Id.*

107. *Id.*

108. *Id.*

other middle school.¹⁰⁹ This matter was settled outside of court and Chadam was allowed to return to Jordan Middle School.¹¹⁰

Although the results of a genetic test are at the center of *Chadam*, GINA did not apply because neither health insurers nor employers were involved, and instead plaintiffs had to “rely on protections against discrimination on the basis of disability, afforded by the Americans with Disabilities Act (ADA) and the Rehabilitation Act of 1973.”¹¹¹ Jennifer Wagner, a lawyer and contributing editor to the Genomics Law Report, stated that “[t]his case is a useful reminder about the limitations of the federal statute.”¹¹²

On September 6, 2013, the Chadams brought suit in federal court.¹¹³ While the Chadams could not bring a suit under GINA because the school was not an employer or health insurer, they alleged other multiple causes of action, including: (1) violation of ADA Title II and (2) violation of Section 504 of the Rehabilitation Act of 1973.¹¹⁴ The school district moved to dismiss both actions and they were granted.¹¹⁵ On appeal, the court reversed these two dismissals.¹¹⁶

Regarding the ADA claim, Chadam’s complaint alleged he was an individual:

(1) who has a disability or is perceived to have a disability; (2) is otherwise qualified to participate in or receive the benefits of a public services, programs, or activities; (3) was either excluded from participation in or denied the benefits of the public entity’s services, programs, or activities or was otherwise discriminated against by the public entity; and (4) was excluded, denied benefits, or discriminated against by reason of his disability.¹¹⁷

The court found that the complaint adequately alleged a violation of the ADA because Chadam:

(1) was perceived as disabled, (2) has a right to attend the closest PAUSD school to his house per PAUSD policy, (3) was excluded from receiving the benefit of that policy because PAUSD deliber-

109. *Id.*

110. *Id.*

111. Dohn, *supra* note 95, at 129.

112. Sarah Zhang, *DNA Got a Kid Kicked out of School—and It’ll Happen Again*, WIRED (Feb. 1, 2016), <https://www.wired.com/2016/02/schools-kicked-boy-based-dna/> [https://perma.cc/WJ3H-9VE6].

113. *Chadam*, 2014 WL 5694080, at *2.

114. *Id.*

115. *Id.*

116. *Chadam v. Palo Alto Unified School District*, 666 F. App’x 615, 616 (9th Cir. 2016).

117. *Id.* at 616–17.

ately removed him from his neighborhood school, and (4) the exclusion was due to his perceived disability.¹¹⁸

The court found that the district court erred in its “direct threat” analysis, that PAUSD acted to preserve the safe operation of the school and thus did not violate the ADA or Section 504, because “[i]n determining whether an individual poses a direct threat to the health or safety of others, a public entity must make an individualized assessment, based on reasonable judgment that relies on current medical knowledge or on the best available objective evidence.”¹¹⁹ Here, PAUSD did not make an individual assessment, but merely relied on the opinion of two doctors who had never even met or treated Chadam to determine he should be removed from the school.¹²⁰ Further, the doctor’s opinion that children with CF should not be in a classroom together was irrelevant because Chadam did not have CF.¹²¹ The school district also did not exercise “reasonable judgment” or use the “best available evidence” because the best evidence would have been Chadam’s medical records that showed that he did not have CF.¹²² Therefore, the school district did not establish a “direct threat” defense.¹²³

The court also held that the district court erred in concluding Chadam’s complaint failed to allege sufficient facts to support the requisite intent.¹²⁴ “The discriminatory intent standard does not require a showing of bad motive, ill will, animosity or, as the district court characterized it, an intent ‘to cause harm and injury.’ Rather, it suffices to allege that PAUSD excluded [Chadam] from a public program because of his perceived disability.”¹²⁵ Facial discrimination in the form of categorical exclusion of disabled persons from a public program is “intentional” by its very nature.¹²⁶

Finally, the court rejected the school district’s additional argument that it did not deny Chadam a “benefit” because there is no “right” to attend a particular school within the district—neither the ADA nor Section 504 requires there to be a denial of a “right.”¹²⁷ Rather, a person who has or who is perceived to have a disability may

118. *Id.* at 617.

119. 28 C.F.R. § 35.139(b) (2019).

120. *Chadam*, 666 F. App’x at 617.

121. *Id.*

122. *Id.*

123. *Id.*

124. *Id.*

125. *Id.*

126. *Id.*

127. *Id.*

not “be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity.”¹²⁸ Here, Chadam was allegedly excluded from participating in, or denied the benefits of, PAUSD’s school services.¹²⁹

Unfortunately, the ADA and Section 504 may offer rather limited protection here as well. Asymptomatic carriers of CF may not be protected by the ADA because there is no disability per se, and “the allegation of cross infection risk might make it difficult for the plaintiffs to prove that discrimination was the sole reason for the transfer, as required by the Rehabilitation Act.”¹³⁰ If a trial goes forward, the outcome in Chadam’s case could “spell out exactly who gets to access genetic information and what decisions can be made based on it.”¹³¹ If the court rules that Chadam’s carrier status is not a “perceived disability” under either of these acts, this “would indicate that public school placement decisions can be based on immutable characteristics.”¹³² Furthermore, since Chadam was only a carrier of the disease, and carriers do not pose a cross-infection risk, this would mean that he was discriminated against solely because of his genetic makeup, resulting in ridicule and humiliation, and that the justification for his transfer to another school was unfounded.

A. State Laws are Also Insufficient in Combatting Genetic Information Discrimination in Public Schools

Existing federal law is not the only source of law upon which students might rely to combat genetic information discrimination. Various states such as California, West Virginia, and Utah acknowledge the use of genetic information in public schools.

California includes genetic information as a protected category in its state civil rights act.¹³³ CalGINA, California’s own genetic information nondiscrimination act, also prohibits denying access to any “program or activity that is conducted, operated, or administered by the state or by any state agency, is funded directly by the state, or receives any financial assistance from the state” on the basis of genetic information discrimination.¹³⁴ Since the California Code of Regulations in-

128. 42 U.S.C. § 12132 (2012).

129. *Chadam*, 666 F. App’x, at 618.

130. Dohn, *supra* note 95, at 129.

131. Zhang, *supra* note 61.

132. Dohn, *supra* note 95, at 129.

133. Cal. Gov’t. Code § 11135 (West, Westlaw through Ch. 340 of the 2019 Reg. Sess.).

134. S.B. 559, 2011 Leg., 2011-2012 Reg. Sess. (Cal. 2011) (enacted by Chapter 261).

cludes “provision of education” in its definition of program or activities, public schools that provide an education would fall under California’s own CalGINA statute.¹³⁵ CalGINA also amended the Education Code to ensure schools have access to additional resources to combat bias and bias-related incidents.¹³⁶ This would theoretically cover biases related to genetic information as well.

However, even with these provisions in place, there are ways to circumvent them. The California Education Code contains a provision similar to the “contagious disease” provision in GINA Title II.¹³⁷ This provision states:

A parent or guardian having control or charge of any child enrolled in the public schools may file annually with the principal of the school in which he is enrolled a statement in writing, signed by the parent or guardian, stating that he will not consent to a physical examination of his child.¹³⁸ Thereupon the child shall be exempt from any physical examination, but whenever there is a good reason to believe that the child is suffering from a recognized contagious or infectious disease, he shall be sent home and shall not be permitted to return until the school authorities are satisfied that any contagious or infectious disease does not exist.¹³⁹

If the student in *Chadam* had CF, this provision would have allowed the school to remove him from the school despite the CalGINA law. Since he did not have CF, the school’s conduct would still be considered lawful if it can prove that it reasonably believed that he had CF or that he posed some sort of threat to the other students.¹⁴⁰ Although this provision is important to the safety of the other students, the “reasonable belief” standard is all too easy for the school district to meet in light of the results of Chadam’s genetic test.¹⁴¹ Moreover, although “contagious” and “infectious” may imply that there must be a risk of harm to the other students to meet the standard, “adding an ‘imminent risk of harm’ component would be prudent to ensure students are only removed if there is truly a reason to do so.”¹⁴²

135. Wood, *supra* note 102, at 318.

136. S.B. 559, 2011 Leg., 2011-2012 Reg. Sess. §4(b) (Cal. 2011) (enacted by Chapter 261).

137. CAL. EDUC. CODE § 49451 (West, Westlaw through Ch. 340 of the 2019 Reg. Sess.).

138. *Id.*

139. *Id.*

140. *Id.*

141. *See generally*, Chadam v. Palo Alto Unified School District, 2014 WL 5694080, at *7 (N.D. Cal. 2014) (indicating that the ease PAUSD had establishing their case was very simple given the other information they already had regarding the Chadam’s child).

142. Wood, *supra* note 102, at 330.

Even with these drawbacks, California seems to be the only state to have implemented any type of genetic information protection in public schools.¹⁴³ West Virginia prohibits the collection of “confidential student information,” which also includes genetic information but it is not explicitly stated.¹⁴⁴ However, even this statute does not address “whether or how a school can use genetic information if it inadvertently obtains it,”¹⁴⁵ like GINA Title II does in the employment context. Moreover, Utah even goes so far as to expressly authorize the use of genetic information in public schools.¹⁴⁶ Utah permits the collection of “students’ biometric identifiers or information on certain conditions.”¹⁴⁷ Biometric identifier is defined as a “human biological sample used for valid scientific testing or screening,” and biometric information is defined as “information . . . based on an individual’s biometric identifier; and [information] used to identify [an] individual.”¹⁴⁸ These definitions might include genetic information because “genetic information is information that can be used to identify an individual.”¹⁴⁹ Therefore, Utah appears to expressly authorize the collection of genetic information in its public schools.

Although these few state laws in California, West Virginia, and Utah acknowledge the use of genetic information in public schools, they fail to provide an adequate level of protection for it.

VI. The Future of Genetic Discrimination Looks Eerily Similar to Disability and Racial Discrimination

Genetic data may start to be used in the way disabilities were treated before the ADA passed, when there were many discriminatory societal barriers that prevented people with disabilities from having access to the various opportunities of everyday life.¹⁵⁰ Furthermore,

143. *Id.* at 320.

144. *Id.* at 319.

145. *Id.*

146. *Id.*

147. *Id.*

148. *Id.*

149. *Id.*

150. *See generally*, ARLENE MAYERSON, *The History of the Americans with Disabilities Act*, DISABILITY RIGHTS EDUCATION & DEFENSE FUND (1992), <https://dredf.org/about-us/publications/the-history-of-the-ada/> [<https://perma.cc/2GZ8-GHAR>] (explaining the long term history of the treatment of individuals with disabilities before the implementation of the Americans with Disabilities act). *See also*, *Chadam v. Palo Alto Unified School District*, 2014 WL 5694080 (N.D. Cal. 2014) (exemplifying what can happen when a school or entity receives the genetic data of an individual).

Some genetic disorders are more likely to occur among people who trace their ancestry to a particular geographic area. People in an ethnic group often share certain versions of their genes, which have been passed down from common ancestors. If one of these shared genes contains a disease-causing mutation, a particular genetic disorder may be more frequently seen in the group.¹⁵¹

For example, sickle cell disease more commonly occurs in individuals of African, African American, or Mediterranean heritage,¹⁵² Tay-Sachs disease is more common in people with Ashkenazi ancestry,¹⁵³ and cystic fibrosis is more common among Caucasians.¹⁵⁴ If entities are allowed to discriminate based on genetic information, this data could be used as a proxy for race, and the same issues with race-based discrimination will appear in genetic information discrimination.¹⁵⁵ At the very least the ADA is a comprehensive statute, and race-based discrimination is subject to strict scrutiny review by courts requiring a narrowly tailored law fit to a compelling governmental interest.¹⁵⁶ The same cannot be said yet for the laws regulating genetic information.

Genetic discrimination is already prevalent in the workplace. The American Civil Liberties Union (“ACLU”) conducted a survey of nearly 1000 individuals who were at risk for genetic conditions, and over twenty-two percent reported that they had experienced some form of discrimination based on their risk status.¹⁵⁷ Even if the ADA covers some cases of workplace discrimination, it does not cover issues with privacy. Currently, there is no federal law that “prohibits an employer from requesting genetic information or testing employees, and no law protecting the privacy of genetic information.”¹⁵⁸ State laws are insufficient in the employment context as well, since so far “only

151. Genetics Home Reference, *Your Guide to Understanding Genetic Conditions*, U.S. NAT'L LIBR. OF MED. (Dec. 11, 2018), <https://ghr.nlm.nih.gov/primer/inheritance/ethnicgroup> [https://perma.cc/G7AF-LZNT].

152. *Id.*

153. *Id.*

154. Patience Akumu, *Is there such a thing as race specific disease?*, THE OBSERVER, Mar. 17, 2010, <https://www.observer.ug/component/content/article?id=7679:is-there-such-a-thing-as-race-specific-disease> [https://perma.cc/ESF9-MQNQ].

155. Vivian Chou, *How Science and Genetics are Reshaping the Race Debate of the 21st Century*, HARVARD UNIVERSITY THE GRADUATE SCHOOL OF ARTS AND SCIENCES (April 17, 2017), <http://sitn.hms.harvard.edu/flash/2017/science-genetics-reshaping-race-debate-21st-century/> [https://perma.cc/B8KE-9AXV].

156. *See generally*, *Adarand Constructors, Inc. v. Pena*, 515 U.S. 200 (1995); *see also*, *Introduction to the ADA*, ADA.GOV, https://www.ada.gov/ada_intro.htm [https://perma.cc/8GP9MG52].

157. *Genetic Discrimination in the Workplace Factsheet*, *supra* note 23.

158. *Id.*

[twelve] states have enacted laws that protect employees from genetic discrimination in the workplace.”¹⁵⁹ As technological advancements allow for more affordable and easier genetic testing, more cases of genetic discrimination will appear.¹⁶⁰ This is why limitations on the use of genetic information by health insurers, employers, public schools, professional sports, and various other entities are needed as soon as possible.

VII. New Regulations Prohibiting the Use of Genetic Information Must Be Implemented

Congress should craft further legislation prohibiting the use of genetic information. First, Congress should clearly define what discrimination means in the context of professional sports and public schools and allow for disparate impact claims. Second, GINA’s protections should extend beyond just health insurers and employers—there must be other titles added that provide protections against genetic discrimination in professional sports and public schools. These new titles’ scope should be expanded to include protections for not only asymptomatic individuals, but also to manifested conditions to fill the gap currently created by GINA’s Title I for health insurers.

A. Suggested New Provisions for GINA

In the context of professional sports, the language of GINA should contain a provision similar to the Organization for Economic Cooperation and Development (“OECD”) Use Limitation Privacy Principle, which states that “collected data must not be used for purposes other than the ones specified at the time of collection.”¹⁶¹ This way, once an athlete’s genetic data is collected by the professional sports team for legitimate purposes, it is limited to that purpose and cannot be used for any other reason that could lead to discrimination.

In the context of schools, although it is true that a symptomatic student may be able to rely on the protections of the ADA instead of GINA, expanding GINA to include *protection for manifested conditions*

159. *Id.* (California, Connecticut, Illinois, Iowa, New Hampshire, New Jersey, New York, North Carolina, Oregon, Rhode Island, Texas, and Wisconsin).

160. Nicole Fisher, *Don’t Mail In That DNA Kit Until You Know These Facts*, FORBES (Mar. 30, 2019, 10:00 AM), <https://www.forbes.com/sites/nicolefisher/2019/03/30/dont-mail-in-that-dna-kit-until-you-know-these-facts/#5bd1860d38e5> [<https://perma.cc/LKF9-LJXY>].

161. Aurélie Pols et al., *OECD Guidelines: 8 Privacy Principles to Live By*, PIWIK PRO (Sep. 21, 2018), <https://piwik.pro/blog/oecd-guidelines-8-privacy-principles-to-live-by/> [<https://perma.cc/AHQ2-8RQQ>].

would make the statute more clear and comprehensive, and more appropriate to bring an action under when the heart of the issue involves genetic information. Admittedly, there should be a disclosure exception for students who are believed to have a contagious or infectious disease in order to protect the safety of other students; however, this exception should be narrow. The language of the exception should mirror GINA's Title II exception for employers by including the word "imminent" rather than using the vague language of the California Education Code. As mentioned earlier, adding the word "imminent" would ensure that students are only removed for just cause.

There should also be a provision *regulating a school official's actions* if a student's genetic information is obtained inadvertently. Despite the fact that GINA's Title II exempts employer liability if the information is obtained inadvertently, the laws should be stricter in the context of public schools, and the protections around young students should be heightened. Although in *Chadam* the school discovered Chadam's genetic information lawfully, there are many circumstances in which this may not be the case.

In the meantime, at the state level, more states should follow California's example and implement protections against the misuse of genetic information for students in their schools.

B. Modeling GINA After Federal Disability Discrimination Statutes

Another way to tackle genetic discrimination would be to model GINA after existing federal statutory law surrounding disability discrimination in public schools. There are three federal laws that "address the obligations of public schools, including charter schools, to meet the communication needs of students with disabilities"¹⁶² in different ways: (1) the Individuals with Disabilities Education Act ("IDEA"), (2) ADA Title II, and (3) Section 504 of the Rehabilitation Act of 1973. Public schools must comply with all three of these laws. Comparisons of these statutes and GINA are discussed below.

1. GINA vs. IDEA

The purpose of IDEA is "to ensure that all children with disabilities have available to them a free appropriate public education that

162. U.S. Dep't of Justice Civil Rights Div., U.S. Dep't of Educ. Office for Civil Rights & Office of Special Educ. and Rehabilitation Servs., *Frequently Asked Questions on Effective Communication for Students with Hearing, Vision, or Speech Disabilities in Public Elementary and Secondary Schools*, ADA.gov, https://www.ada.gov/doe_doj_eff_comm/doe_doj_eff_comm_faqs.htm [https://perma.cc/VA2Q-G853].

emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living.”¹⁶³ Under the IDEA, federal funds are provided to school districts through state educational agencies.¹⁶⁴ The states receiving these funds

must ensure that school districts locate, identify, and evaluate children who are suspected of having disabilities and who need special education and related services.¹⁶⁵ Each eligible child must have a written individualized education program (IEP), developed by an IEP Team, that, among other things, includes a statement of the special education and related services that the school district will provide to the child.¹⁶⁶

IDEA explicitly covers thirteen disability categories.¹⁶⁷ Congress should do the same for genetic discrimination. Congress has the power to implement a law that first identifies certain diseases or conditions in need of more protection (perhaps the conditions that are more prevalent among certain races such as sickle cell anemia or Tay-Sachs disease), and then ensures that all children with these diseases or conditions in federally-funded school districts have a free appropriate public education that is tailored to suit their unique needs through an IEP.

2. GINA vs. ADA Title II

ADA Title II states that “no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity.”¹⁶⁸ This means “disabled students must have access to all of the educational benefits, services, and programs. Failure to construct new buildings

163. 20 U.S.C. § 1400(d)(1)(A) (2012).

164. *Overview of Funding for Pre-K-12 Education*, AM. SPEECH-LANGUAGE-HEARING ASS’N, <https://www.asha.org/Advocacy/schoolfundadv/Overview-of-Funding-For-Pre-K-12-Education/> [https://perma.cc/S6LL-HWNM].

165. U.S. Dep’t of Justice Civil Rights Div., U.S. Dep’t of Educ. Office for Civil Rights & Office of Special Educ. and Rehabilitation Servs., *supra* note 162.

166. *Id.*

167. Andrew M. I. Lee, *Individuals With Disabilities Education Act (IDEA): What You Need to Know*, UNDERSTOOD, <https://www.understood.org/en/school-learning/your-childrens-rights/basics-about-childrens-rights/individuals-with-disabilities-education-act-idea-what-you-need-to-know> [https://perma.cc/KW8K-KCYQ].

168. 42 U.S.C. § 12132 (2012).

and update older buildings in order to ensure access is a violation under the ADA.”¹⁶⁹

This is one of the federal statutes that the Chadams relied on in *Chadam*.¹⁷⁰ An equivalent law can be set in place for genetic discrimination by substituting the word “disability” with “genetic disease or condition, either manifested or not-yet-manifested.” This would ensure that students showing symptoms of a disease would be protected just as well as students only carrying the gene related to a certain disease.

3. GINA vs. Section 504

The purpose of Section 504 of the Rehabilitation Act of 1973 is to ensure, to the greatest extent possible, that youth with disabilities and students with disabilities who are transitioning from receipt of special education services under the Individuals with Disabilities Education Act (20 U.S.C. 1400 et seq.) and receipt of services under section 794 of this title have opportunities for post-secondary success.¹⁷¹

This means that “educational institutions are required to make reasonable accommodations to help disabled students perform effectively. The goal is that the disabled students have equal access as those students without disabilities.”¹⁷²

This is one of the other acts that the Chadams had to rely on in *Chadam*.¹⁷³ Congress can enact a similar law that mandates reasonable accommodations for students who have either a manifested or not-yet-manifested disease or condition.

Between the IDEA, ADA Title II, and Section 504, protections for disabilities have been thoroughly covered in public schools. The same must be done for genetic discrimination. Congress must implement a law that first identifies certain diseases or conditions in need of protection, and then it must condition federal funding on public schools’ providing equal opportunities to students with these conditions. For other genetic disorders not included on the list, there should be similar protections in place. At the very least, Congress can use discrimina-

169. *Discrimination in Education – Federal Laws*, FINDLAW, <https://civilrights.findlaw.com/discrimination/discrimination-in-education-federal-laws.html> [https://perma.cc/BN4E-767P].

170. *Chadam v. Palo Alto Unified School District*, 2014 WL 5694080, at *1 (D. N.D. Cal. 2014).

171. 29 U.S.C. § 701(b)(5) (2012).

172. *Discrimination in Education – Federal Laws*, *supra* note 169.

173. *Chadam*, 2014 WL 5694080, at *1.

tion in the context of disabilities to help define what discrimination would mean in the context of genetic information. Congress should add protections here specifically because the discrimination that GINA seeks to prevent is fundamentally different from any other type of discrimination. This is because the discrimination being effectuated is based on conditions that are not actually present, but only have a propensity or increased likelihood of being present. Even if a genetic test accurately predicts a condition, the test will not indicate when symptoms will develop or the severity of the symptoms. This makes genetic information worthy of the utmost protection.

VIII. Conclusion: There Should Be Stricter Laws Surrounding the Use of Genetic Information

Although there are many benefits to genetic testing and the use of genetic information, genetic data is too important to only receive basic statutory protection. The potential for abuse of this information is too great to leave it with the minimal protection that now exists. To resolve the problem, the scope of GINA's protection should be expanded to provide coverage in professional sports and public schools. This new provision should clearly define discrimination in these contexts and include disparate impact claims. It should provide thorough coverage for both asymptomatic and symptomatic individuals. This new provision can be modeled off existing federal statutory laws surrounding disability discrimination. Congress should amend GINA to address these concerns immediately, as genetic discrimination is an emerging issue of utmost importance.