From Nucleotides to Nuanced Law: The Value of an Incremental Approach to Experimentation in State-Level Genetic Anti-Discrimination Legislation

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From Nucleotides to Nuanced Law: The Value of an Incremental Approach to Experimentation in State-Level Genetic Anti-Discrimination Legislation

Katelyn Fisher

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ABSTRACT
A person’s genetic information tells a detailed story of what someone looks like, who her relatives are, and even what illnesses she may develop. This information, as enlightening as it may be, can be especially damaging when utilized in a discriminatory way. This Note explores how the protections under the Genetic Non-Discrimination Act of 2008 will no longer be sufficient for protecting individuals from genetic discrimination as the use of genetic information becomes more commonplace. The questions become: Where do we start? How and where should protections that extend to circumstances not covered by GINA be created in a way that results in comprehensive protections against genetic discrimination? This Note proposes that an effective way to achieve comprehensive protection is through incremental change in genetic anti-discrimination law at the state level before legislative change is attempted at the federal level. It argues that experimentation in the laws at the state level will allow for thorough and meaningful protections by allowing the concerns regarding genetic discrimination in the individual states to catalyze their legislative responses and will allow the states to learn from other states in determining effective paths for its own genetic non-discrimination legislation. Finally, this Note will explore potential legal frameworks that states could use as a model for genetic anti-discrimination legislation.

AUTHOR’S NOTE
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I. INTRODUCTION

At the brink of the new millennium, the movie *Gattaca* hit theaters. The film recounts the story of a young man shunned from society and disqualified from lucrative employment because he was not scientifically crafted to be the genetic highlight reel of his parents. *Gattaca* seemed like a science fiction exaggeration, a mere reflection of what the world could become given the modern scientific advancements in genetics. In actuality, *Gattaca* emulated what was beginning to occur in the real world. Technological advancements, like predictive medicine, have since propelled genetics to the scientific forefront, making human genetic data readily available.

A person’s genetic data has the potential to significantly advance their medical treatment and biological self-understanding. However, use of that data may extend beyond the intended medical setting and into contexts where it may be used to her detriment. When genetic data reveals that a person is predisposed to disease, that fact could be honed into a tool of discrimination in the issuance of health insurance policies, employment, mortgage lending, and education, as just a few possibilities. With concerns regarding the use of medically acquired genetic data in nonmedical contexts becoming more prevalent,

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2. *Id.*
3. *Id.*
4. See Michael R. Dohn, *Personal Genomics and Genetic Discrimination: Is Increased Access a Good Thing?*, 45 W. St. L. Rev. 107, 109–10 (2018) (explaining the history behind the discriminatory use of genetic information). “[The Eugenics] movement advocated for the sterilization of ‘undesirable’ individuals with the goal of improving the genetic composition of the population as a whole.” *Id.* This occurred in the early twentieth century in over 30 states, and “undesirable individuals” included those with physical or mental disabilities. *Id.* at 110. These laws have since been repealed, but in the 1970’s there was a rise in states requiring genetic tests for sickle cell anemia in African Americans and following that were discriminatory practices against those who possessed the gene. *Id.* at 110–11.
5. *Id.* at 112.
6. See *id.* at 112–13; see also Chadam v. Palo Alto Unified Sch. Dist., 666 Fed. App’x 615, 615 (9th Cir. 2016) (detailing how a student was removed from school due to the school’s belief that he had cystic fibrosis, when in actuality he merely had the genetic marker for the disease).
7. See, e.g., Dohn, supra note 4, at 113 (describing the lack of limitations on the use of genetic information in determinations related to health insurance policies as a potential drawback).
Congress enacted the Genetic Information Nondiscrimination Act (“GINA”) in 2008. This Act created narrow protections for the use of genetic data in employment practices and health insurance determinations. GINA prevents both employers and health insurance companies from purchasing, requesting, or requiring an individual’s genetic information and from generally utilizing the information in a discriminatory fashion.

Though GINA provides limited protections against genetic discrimination, it fails to protect against instances of genetic discrimination in other industries. The potential use of genetic information in forums outside of the employment and insurance arenas is, as Gattaca demonstrated, astounding. Considering this, what is the legal remedy for a child who is denied equal access to education based on a genetic predisposition to a disease that has not physically manifested? What protections are afforded to a person who is denied a mortgage due to a genetic marker for a disease which may result in premature death, but for which they are only mildly symptomatic?

9 See generally id. (setting forth the protections against genetic discrimination in health insurance and employment).
10 Id. at § 101(d)(1)–(2).
11 See Anya E. R. Prince & Benjamin E. Berkman, When Does an Illness Begin: Genetic Discrimination and Disease Manifestation, 40 J. L. MED. & ETHICS 655, 657–58 (2012) (arguing that GINA is both limited in scope and also fails to define at what point a disease is considered physically manifested and therefore no longer protected under GINA); see also Dohn, supra note 4, at 113 (highlighting the limited areas of GINA’s protection).
12 E.g., Chadam v. Palo Alto Unified Sch. Dist., 666 Fed. App’x 615, 615 (9th Cir. 2016). Though there was a remedy for this child under the ADA, the situation is possibly predictive of other similar situations where protection under the ADA may not be available. See Prince & Berkman, supra note 11, at 657 (under either GINA or the ADA, “[t]here is arguably no protection for individuals who have manifested some symptoms, but whose symptoms have not risen to the level of substantial limitations”).
13 See Prince & Berkman, supra note 11, at 657–58. “GINA was structured such that it only provides protection against misuse of genetic information up until the point when an individual’s disease has manifested. It protects an individual with a genetic predisposition for a disease, but not an individual actively suffering from that disease.” Id. at 655. The point where a disease is considered to have manifested for GINA protection purposes is not defined in GINA. Id. This creates a gray area of situations where people may not be protected under GINA, as “there will be a gap between when an asymptomatic individual will be protected by GINA and when their symptoms will rise to the definition of disability protected under the Americans with Disabilities Act (ADA).” Id. at
GINA leaves such questions unanswered, and looking to the future, the actions in response to these questions could become devastating instances of discrimination based on genetics that do not currently have an adequate legal remedy.14

As science evolves, laws governing genetic data must evolve alongside it. Experimentation—in both science and legal policy—values adaptation and learning from applied experience to build on existing knowledge from past outcomes.15 This inherent need for flexibility in the law lends itself well to legislation at the state level.16 As the availability and knowledge of genetic data evolves from its relative legal infancy, the nature and extent to which genetic discrimination will ultimately manifest is unknown.17 Legal reform at the federal level requires some consensus among the states. Due to the amount of time that will surely transpire before genetic discrimination is recognized in areas beyond health insurance and employment, trying to combat it at the federal level would be overly complex and cumbersome.18 In 2008, the breadth of areas in which genetic discrimination could arise was not concretely established, and if specific contexts were considered they were not regarded as

657. A person is protected from discrimination based on a disability under the ADA if they have “symptoms [that] substantially limit a major life activity.” Id.

14 See Dohn, supra note 4, at 126 (“[GINA] ‘does nothing to prohibit discrimination in life insurance, disability insurance, long term care insurance, or commercial transactions.’ The Act also does not address genetic discrimination in the public education system or in housing.”).

15 Cf. James W. Fosset et al., Federalism & Bioethics: States and Moral Pluralism, 37 HASTINGS CTR. REP. 24, 25 (2007) (discussing the benefits of a federalist approach to bioethics reform as “offer[ing] considerable advantages in managing the political conflicts that inevitably arise from moral pluralism, particularly around questions where there is no clear national consensus.”).

16 Id. States can manifest the ability to adapt to political and moral conflict and can be strengthened through incremental legislative experimentation. See infra note 128.

17 See Jessica L. Roberts, Preempting Discrimination: Lessons from the Genetic Information Nondiscrimination Act, 63 VAND. L. REV. 439, 481 (2010) (arguing that basing legislation on fear of future harms is problematic, as “Congress is incapable of anticipating how the discrimination will actually operate if it indeed occurs”).

18 Cf. Fosset et al., supra note 15, at 28 (in the context of bioethics generally, states can deal with interstate policy variations and “are able to take action on complex and controversial bioethical issues if the federal government is unable to do so”).
sufficiently problematic to warrant protection. The states will vary in their recognition of genetic discrimination as a pervasive issue in areas GINA does not cover; and this disjunction of time and scope of coverage makes a federal consensus unlikely.

A state-by-state experimental approach offers a method of legal advancement which reconciles the need for more comprehensive genetic antidiscrimination legislation with the unpredictable nature of the field to be regulated. States could enact laws tailored to local discrimination issues that not only go beyond GINA’s limited protections, but could also serve as a legislative blueprint for other states to adopt as applicable. This represents an incremental approach; relying on smaller, specific instances of experimentation at the state level to respond to the prospective issues that genetic discrimination presents, thereby advancing the progress of comprehensive genetic antidiscrimination legislation.

This Note will begin with the history of genetic research and how science has led to the modern uses of genetic material. It will then address the federal response to the increasing use and prevalence of genetic information by passing GINA, and how the momentum of scientific advancements has rendered GINA’s protections inadequate. This Note proposes that protections beyond GINA must come in the form of state-level legislation and focuses on the need for changes in the state laws to be made in a deliberate, incremental fashion so states have the freedom to experiment before the enactment of a comprehensive federal law. The discussion then turns to the benefits of using this approach to facilitate the legislative changes and will

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20 Cf. Fosset et al., supra note 15, at 25 (“state legislatures and courts have been and continue to be major participants in the establishment and implementation of bioethics policy”).
21 Id.
22 Cf. Robert A. Mikos, The Evolving Federal Response to State Marijuana Reforms, 26 WIDENER L. REV. 1, 18 (2020) (when creating legislation, in the context of federal marijuana regulation, it is “easier for a legislature to build consensus behind a narrow, targeted measure” rather than “more comprehensive reforms”).
conclude with models the individual states could follow as they develop genetic nondiscrimination legislation.

II. THE RISE OF THE UNDERSTANDING AND USE OF GENETIC INFORMATION

While the complex mapping of the human genome was a monumental accomplishment in science, it was also a slow and painstaking process.24 Like most scientific discoveries, as the understanding of the human genome deepened, so did its application.25 It is true that some of the uses of genetic information are relatively benevolent, aimed at improving medical treatment with recommendations based on the person’s unique genetics.26 The fear is that this newfound accessibility of genetic data also invites invasions of privacy and discrimination.27 Consequently, the federal government enacted GINA, which prohibits discrimination based on genetics in employment and health insurance settings.28 The continued scientific advancements in this field will inherently result in genetic information being more readily accessible than ever before, making GINA’s limited protections ineffective.29

A. Brief History of Genetic Information

Through a scientific lens, a human’s “genetic information” is relatively straightforward: it refers to the entirety of the human genome. The genome is a sequence of millions of chemical building blocks (DNA), constructed in a way that is unique to each individual,

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25 Id.
26 Id.
27 Genetic Information Nondiscrimination Act of 2008 § 2, 42 U.S.C. § 2000ff (2018); see also Roberts, supra note 17, at 480–81 (discussing that the creation of GINA was predicated on a fear of genetic discrimination in the workplace and by health insurance companies).
28 See generally Genetic Information Nondiscrimination Act.
and controls all the physical characteristics of a particular person.\textsuperscript{30} The United States government started the Human Genome Project in 1990 for the purpose of identifying all human genes.\textsuperscript{31} Spanning nearly fifteen years, the Project was completed in 2003 and disclosed the sequence of nearly the entire human genome.\textsuperscript{32} Genetic information is the foundation for every function in the human body, it determines both basic attributes (hair or eye color) and the most complex of bodily processes (protein creation).\textsuperscript{33} Apart from being indicative of a person’s basic traits, genetic information can also be considered to tailor medical treatment methods and predict health conditions.\textsuperscript{34} In a sense, genes are a window into a person’s medical future because they reveal predispositions to potential illnesses.\textsuperscript{35}

As with any prediction, genes do not relay certainty, a person may possess a gene signaling an increased risk for an illness or disease that might never actually manifest.\textsuperscript{36} Thus, the use of a person’s genetic data could lead to discrimination based on an illness she never actually

\begin{footnotesize}
\begin{enumerate}
\item Phenotype, NAT’L HUM. GENOME RES. INST., https://www.genome.gov/genetics-glossary/Phenotype [https://perma.cc/2Z98-MML4] (explaining the different characteristics controlled by genes); see also Dohn, supra note 4, at 112–13 (discussing how DNA collected in at-home testing kits can be used to discover various characteristics about an individual).
\item Areheart & Roberts, supra note 34, at 719.
\item A Brief Guide to Genomics, supra note 30 (explaining that genetics play a role in the manifestation of disease, but their manifestation may be subject to the influence of environmental factors).
\end{enumerate}
\end{footnotesize}
experiences; and would have remained uncovered but for the scrutiny of her genes.

**B. Genetic Discrimination**

The legal classification of genetic information is far more complex than its scientific counterpart. From a legal standpoint, genetic information encompasses an individual’s genetic tests, which include any test that analyzes a person’s DNA to provide information regarding the individual’s genetic sequence, genetic mutations, and changes in their genome.\(^{37}\) It also includes the genetic data and “manifestation of a disease or disorder” in that individual’s family members.\(^{38}\)

The broad scope of the legal definition of genetic information is indicative of the problems presented by its unregulated use and highlights the fields which require legal protection.\(^{39}\) The conclusions that can be drawn about an individual from the genetic and health data of their relatives creates an array of privacy concerns.\(^{40}\) Genetic privacy concerns are heightened by the sensitive information it can reveal about an individual. Genes can express not only predispositions for illness and disease, but other traits that a person may desire to keep private, such as stigmatized personality traits like addictive tendencies and aggression.\(^{41}\) Considering that the genetic information from one person could be indicative of their entire family’s genetic information, it has the potential to trigger the discrimination of an entire group of people.\(^{42}\)

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\(^{38}\) *Id.* at § 201(4)(A)(iii).

\(^{39}\) *See* Dohn, *supra* note 4, at 126–27 (identifying several categories that are outside the scope of GINA where protection against genetic information discrimination should be required).

\(^{40}\) *Id.*

*See* Jessica L. Roberts, *The Genetic Information Nondiscrimination Act as an Antidiscrimination Law*, 86 NOTRE DAME L. REV. 597, 616–17 (2011) (highlighting the collection of genetic information as a privacy concern based on the availability of sensitive information); *see also* Andreas Meyer-Lindenberg et al., *Neural Mechanisms of Genetic Risk for Impulsivity and Violence in Humans*, 103 PROC. OF THE NAT ACAD. OF SCI. 6269, 6272 (2006) (explaining the complexities of correlating the prevalence of certain genes with increased levels of aggression given the presence of other factors including environmental and social).

\(^{42}\) Roberts, *supra* note 41, at 617.
For those individuals with genetic predispositions that do manifest and can be diagnosed, protections against discrimination may exist under the Americans with Disabilities Act (“ADA”). The ADA provides protections for people based on both physical and mental disabilities. However, protections for genetic predispositions to disease that do not manifest are not within the scope of the ADA.

Protections for people with unmanifested-but-potential medical issues identified through genetic sequencing were comparatively absent before the enactment of GINA, as the pervasive potential of genetic information usage was only beginning to arise. This expansion of genetic information in the medical field highlighted a new form of possible discrimination predicated on the mere possibility of illness occurring. For instance, historically, health insurance companies were not barred from considering a person’s genetic predisposition for health conditions when deciding whether to issue a policy. Health insurance providers were apt to raise prices to cover illnesses a person was predisposed to or even deny issuing a policy based on genetic markers and predispositions. It was the vulnerability of individuals in cases like this that prompted the enactment of GINA.

C. The Enactment of GINA

In 2008 Congress noted a “current explosion in the science of genetics,” which motivated them to enact GINA as a proactive measure to combat genetic discrimination. The concerns over

43 See Prince & Berkman, supra note 11, at 657 (protection is dependent on satisfying the definition of disability under the Act).
44 See id. (ADA is limited to protecting symptoms that substantially limit major life activity).
45 Id.
46 See id. at 655 (GINA was enacted in response to technological advancements in genetic science).
47 See id. at 655–56.
48 See Areheart & Roberts, supra note 34, at 722 (discussing the lack of protection for genetic discrimination by health insurers before both GINA and the Affordable Care Act).
49 Id.
50 Id. at 723–24.
51 Genetic Information Nondiscrimination Act of 2008, 42 U.S.C. § 2 (2018); Roberts, supra note 41, at 625 (“GINA is a forward-looking statute—designed to preempt a variety of discrimination before it becomes entrenched”).
potential discriminatory uses of genetic information came on the tails of the Human Genome Project being started. GINA was originally introduced in Congress by Representative Louise Slaughter in 1995 and included protections against genetic discrimination in health insurance, but the bill died before it could be voted on by Congress. The bill was reintroduced in 1999 with the additional protection against genetic discrimination in employment but it failed to pass both houses of Congress once again. The 1999 bill was reintroduced in 2002 by Senator Olympia Snowe. After two more unsuccessful introductions, GINA was signed into law in 2008.

The scope of GINA is highly limited, concerning only the “misuse of genetic information in health insurance and employment.” In the context of health insurance, GINA prohibits health insurance companies from “request[ing], requir[ing], or purchas[ing] genetic information for underwriting purposes.” In the area of employment, employers cannot “request, require, or purchase genetic information with respect to an employee or a family member of the employee.” Additionally, GINA generally proscribes an employer from discriminating against an employee on the basis of their genetic information.

Outside of prohibiting employers and health insurers from purposefully gathering genetic information and using that information to explicitly discriminate against people, GINA leaves much to be desired. Even the limited protections that are granted are subject to exceptions and thus not entirely comprehensive. For example, GINA does not provide recourse when health insurance companies

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52 See SARATA & FEDER, supra note 31, at 3–4.
53 See Timeline of the Genetic Information Nondiscrimination Act (GINA), supra note 32.
54 Id.
55 Id.
56 Id.
58 Id. § 101(d)(1).
59 Id. § 202(b).
60 Id. § 202(a).
61 Roberts, supra note 41, at 640.
62 See, e.g., Roberts, supra note 17, at 456–57.
incidentally acquire a person’s genetic information.\textsuperscript{63} Apart from this limited coverage, genetic-based discrimination remains unchecked and unpunishable in other circumstances.

\textbf{III. FEDERAL AND STATE ATTEMPTS TO ADDRESS THE SHORTFALLS LEFT BY GINA}

As expressed in the congressional findings of GINA, the science of genetics is continually evolving which, in turn, expands the potential use for genetic information.\textsuperscript{64} As a result, even though GINA was meant to afford individuals protections against genetic discrimination in the employment and health insurance fields it does nothing to prevent genetic discrimination in other environments.\textsuperscript{65} For example, a school in California was accused of removing a young male student because he had a genetic marker that predisposed him to cystic fibrosis.\textsuperscript{66} In that case, the school perceived the student as having a disability because of his predisposition and removed him based on that perception, which the court held was prohibited under the ADA.\textsuperscript{67} This example of genetic discrimination in education showcases just one of the venues not covered by GINA. But what would happen if the genetic predisposition were for a characteristic that could not be perceived as a disability under the ADA, like aggression?\textsuperscript{68} What remedy is available for the person who is denied being considered as a foster parent because they are predisposed to aggression? Given the continuous advancements in technology and science, this is likely to be just one of a myriad of instances of genetic discrimination not currently prohibited by law.\textsuperscript{69}

GINA is not a comprehensive statutory scheme and contains several notable exceptions in the fields it does cover. In employment,

\begin{footnotesize}
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\item Id. at 456.
\item Genetic Information Nondiscrimination Act § 2.
\item See \textit{id}.
\item Chadam v. Palo Alto Unified Sch. Dist., 666 Fed. App’x. 615, 616 (9th Cir. 2016).
\item Id.
\item See \textit{generally} Meyer-Lindenberg et al., \textit{supra} note 41, at 6272 (illustrating the correlation between an individual’s genes and a predisposition for violent behavior and aggression). Because the predisposition for aggression is not a manifestation of a disability, it is unlikely to be covered by the ADA. \textit{See} Prince & Berkman, \textit{supra} note 11, at 657.
\item See \textit{Dohn}, \textit{supra} note 4, at 128–29.
\end{enumerate}
\end{footnotesize}
GINA fails to prohibit the military from utilizing genetic information of applicants in the hiring process. Nor does the Act extend to employers with fewer than fifteen employees. As for health insurance, GINA does not cover affiliate realms such as life insurance, long-term care insurance, or disability insurance. As it stands, many employers and the health insurance equivalents are not prohibited from considering an individual’s genetic information.

Other federal laws minimally supplement the provisions of GINA. The Health Insurance Portability and Accountability Act (“HIPAA”) is a law that governs health-related information privacy. With the passage of GINA, HIPAA now includes genetic information within the umbrella of health information, so it cannot be considered by health insurance providers when determining plans and premiums. GINA could also possibly be supplemented by the ADA, which prohibits discrimination in several settings, including employment and public accommodations. In 1995, the Equal Employment Opportunity Commission (“EEOC”) interpreted the ADA to cover “genetic information relat[ed] to illness, disease, or other disorders.” Additionally, the EEOC considered that the ADA could be applicable to preventing genetic discrimination in employment settings. Finally, GINA is supplemented by the Affordable Care Act of 2010 (“ACA”). The Act requires health insurance companies to provide health insurance coverage to any person who requests it. Additionally, the ACA indirectly prohibits considering genetics when determining the cost of coverage by excluding genetics from the

70 Genetic Discrimination, supra note 29.
71 Id.
72 Id.
73 Id.
74 Id.
75 Id. Unfortunately, HIPAA only protects the privacy of genetic information in health insurance settings. Id.
76 Id.
77 Id.
78 Id. It is important to note that the interpretation by the EEOC does not legally mandate a court to interpret the ADA as including genetic discrimination, and its legal application is unknown as case law has not yet developed on the subject. Id.
79 Id.
80 Id.
narrow list of factors companies may use to vary the price of a policy.\textsuperscript{81}

Most states have adopted similar restrictions to those included in GINA.\textsuperscript{82} However, some states go further and provide protections against genetic discrimination in venues beyond GINA’s coverage.\textsuperscript{83} While this “small handful of states” have legislation governing the disclosure of genetic information, they lack antidiscrimination legislation specifically for genetic information.\textsuperscript{84} Yet the existence of such legislation by the states clearly demonstrates their increasing appreciation of the unique dangers attendant to the misuse of genetic information.

As the legal concept of genetic discrimination remains nascent, the states affording more protection against genetic discrimination than GINA offer insight into the areas that some states recognize as requiring additional protection. For example, California has enacted the California Genetic Information Nondiscrimination Act (“CalGINA”),\textsuperscript{85} which integrated the prohibition against genetic discrimination into its civil rights law, making it unlawful to discriminate against a person based on their genetics in all state-funded business practices.\textsuperscript{86} This includes industries such as housing, mortgage lending, and education.\textsuperscript{87} This approach to adopting laws varying in degrees of protection, comparative to GINA, may result in a patchwork of protections among the states, but it may also achieve a comprehensive framework long before the federal law catches up.\textsuperscript{88}

\textsuperscript{81} Id. (health insurers are permitted to change premiums based on limited factors such as age and area of residence).
\textsuperscript{82} See generally Sally J.T. Necheles, Cause of Action for Violation of the Genetic Information Nondiscrimination Act, 71 CAUSES OF ACTION 2D 537 § 73 (Supp. 2020) (illustrating the existing various state variations of GINA).
\textsuperscript{83} Dohn, supra note 4, at 124.
\textsuperscript{84} See id. (Alaska, Arizona, California, Florida, and Nevada, deal with genetic information in the context of privacy rather than discrimination).
\textsuperscript{85} CalGINA, ch. 261, 2011 Cal. Stat. 2774 (codified in scattered sections of the California Codes).
\textsuperscript{86} Id.
\textsuperscript{87} See Areheart & Roberts, supra note 34, at 725 n.58 (discussing the protections against genetic discrimination afforded under CalGINA).
\textsuperscript{88} Cf. Summer Johnson, Editorial, Federalism, Federalism Everywhere, AM. J. BIOETHICS, Nov. 2008, at 1–2 (in the context of state law governing human research subjects, “[p]erhaps national consensus will emerge from the states”). It follows that one possible outcome of state level experimentation in the law governing genetic discrimination could result in a common understanding of the
IV. INCREMENTALISM AS A PROPOSED SOLUTION

Considering the shortfalls within GINA and the ever-expanding use of genetic information, legislative change is warranted. There are two major benefits to starting this change at the state level. First, state-level legislation is less daunting and can be enacted faster than federal law. Second, incremental legislation allows for experimentation that can result in a framework of laws which represent the specific needs of the individual states to combat genetic discrimination.\(^89\)

A. State-Level Experimentation to Effectuate the Creation of Genetic Antidiscrimination Laws

An incremental approach to genetic antidiscrimination legislation would both accurately reflect the needs of the several states in providing protection to their citizens and catalyze change in the law sooner than federally-enacted legislation.\(^90\) More specifically, this state-level experimentation would foster both progressive awareness and recognition of genetic discrimination as a growing cause for concern.\(^91\) The focus on creating genetic anti-discrimination legislation at the state level could avoid two issues that may arise if the law were initially enacted at the federal level. First, making changes at the state level could ameliorate the slow pace of federal legislation related to genetic discrimination. Second, this approach could help close the inevitable gaps that result from enacting federal legislation in a developing area of law.\(^92\)

Federal anti-discrimination statutes provide a uniform framework that specifies precisely which areas of society lawmakers considered merited protection. This uniformity would be particularly ineffective for our purposes because the varying degrees to which states encounter genetic discrimination would make it difficult to reach a consensus on

\(^{89}\) Lindblom, supra note 23, at 85 (“small variations from present policy makes the most of available knowledge”).

\(^{90}\) See Fosset et al., supra note 15, at 25.

\(^{91}\) See Lindblom, supra note 23, at 85.

what areas to protect. If the federal government decided to update
and expand current genetic antidiscrimination legislation, the process
would be laborious. In the time it would take for the bill to be
proposed, debated, and enacted, new areas of discrimination would
likely surface and be excluded from protection. This leaves the
federal legislature in a challenging position: attempt to pass a general
legislative ban on genetic discrimination or predict other industries
where protections against genetic discrimination may be warranted.
Both options could result in insufficient protections because the law, at
some point, must yield to the unpredictability of scientific
advancement.

Implementing genetic antidiscrimination laws at the state level
would advance the understanding of circumstances that may require
protection, and provide each state the opportunity to craft specific laws
based upon what protections are necessitated. Individual states are
more familiar with the unique needs desires, and limitations of their
constituents because of their proximity to them. This connection
allows for genetic antidiscrimination laws governing different
instances of discrimination to be enacted more efficiently in the

93 Cf. Fosset et al., supra note 15, at 28 (discussing how states are better equipped
to handle a lack of national consensus in the field of bioethics due to a more
intimate understanding of local values and practicalities).

94 Cf. id. at 32 (in the context of stem cell research a “decentralized pattern of
policy development also provides a desirable means to develop national
answers”). In an area of law where there is unlikely to be national answers, the
will of the people regarding genetic discrimination legislation would be better
reflected if the law was changed at a level most intimate with the needs of the
citizens. Id. at 28.

95 Cf. id. at 27–28 (political “cross-pressures” on the national level can make
federal action impossible and therefore put states in a better position to pass
comprehensive legislation on important issues).

96 Cf. id. at 30 (“Allowing for variations in program structure and implementation
both permits the tailoring of program management to local conditions and
allows other states and the federal government to gain valuable information on
the most effective means of improving program performance.”); Kathryn L.
Tucker, Federalism in the Context of Assisted Dying: Time for the Laboratory to
Extend Beyond Oregon, to the Neighboring State of California, 41 WILLAMETTE
L. REV. 863, 879–80 (2005) (Oregon serving as a laboratory for the possibility
of physician-assisted dying).

97 Fosset et al., supra note 15, at 28.
individual states. A state has the opportunity to act swiftly to propose legislation prohibiting discrimination from continuing within the state, which promotes a government that is “more immediately accountable to individual[]” citizens of that state. If protections were enacted at the federal level the long waiting periods would allow the discrimination to perpetuate in unprotected areas, compounding the injury to those subjected to the discrimination. Furthermore, fears over the unregulated use of the genetic information could chill the progression of genetic advancements.

Enacting legislation at the state level could offer greater protections to the citizens of individual states without violating their rights under federal law. The Supremacy Clause of the United States Constitution prevents states from reducing protections provided by federal law. However, state laws that add protections to the floor established by GINA would not conflict with federal law. With this in mind, citizens would enjoy increased protections under both the federal and state laws. This model will result in framework of protective legislation that is more comprehensive in a wider breadth of settings than GINA.

98 See Johnson, supra note 88, at 1 (arguing that in bioethics, states may enact needed regulations if the federal government is failing to do so or is not doing it fast enough).


100 See Roberts, supra note 41, at 603–06 (GINA was passed as a way to mitigate fears associated with unregulated use of genetic information and to encourage participation in genetic testing to improve research and benefits to individuals); see also Annet Wauters & Ine Van Hoyweghen, Global Trends on Fears and Concerns of Genetic Discrimination: A Systematic Literature Review, 61 J. HUM. GENETICS 275, 279–81 (2016) (discussing modern fears of genetic discrimination of specific genes).

101 Preemption, CORNELL L. SCH.: LEGAL INFO. INST., https://www.law.cornell.edu/wex/preemption [https://perma.cc/DC79-Z2EW]. This means any state law that affords less protection than GINA directly conflicts with federal law and is unenforceable. Id.

102 Id.


104 See id. CalGINA provides significant protections beyond the scope of GINA while retaining GINA protections.
There are likely endless ways in which genetic discrimination could manifest as science in the field continues to develop.\textsuperscript{105} States and their respective legislatures and citizens, may differ in their perspective of which rising issues should be a priority for legislative action.\textsuperscript{106} The law in this sense is analogous to the human genome: variation leads to evolution.\textsuperscript{107} The power of a state to enact genetic anti-discrimination legislation is within the state’s general “police power,” which allows the state to create regulations controlling the welfare of its citizens so long as the law does not conflict with established federal laws.\textsuperscript{108}

Consider the implications of the following example. State A is experiencing a significant issue with the usage of genetic information for prejudicial purposes by its banks, which are considering the genetic data of applicants when deciding whether to issue a loan or rejecting loans for those who have the genetic marker for a disease.\textsuperscript{109} Under this Note’s proposed model, State A may identify the discriminatory conduct, and propose and enact legislation that would prevent it from continuing in that setting. Subsequently, if State B is experiencing the same issue, it may either implement legislation using State A as a blueprint, or it could enact its own unique legislation. States where citizens are experiencing genetic discrimination more pervasively can serve as models for how such discrimination is handled so other states

\textsuperscript{105} See Fosset et al., supra note 15, at 29 (“[A]n active role for states in developing and implementing bioethical policy provides for experimentation in the design and implementation of complex bioethical decisions.”).

\textsuperscript{106} See id. at 28 (“Federalism tolerates great diversity in domestic policy . . .”).

\textsuperscript{107} Tucker, supra note 96, at 879 (Experimentation in bioethics law in the context of assisted dying “is exactly what Justice Brandeis contemplated in his famous passage: ‘[i]t is one of the happy incidents of the federal system that a single courageous state may, if its citizens choose, serve as a laboratory and try novel social and economic experiments without risk to the rest of the country.’” (quoting New State Ice Co. v. Liebermann, 285 U.S. 262, 311 (1932) (Brandeis, J., dissenting))).


could then emulate that approach.\textsuperscript{110} This allows the states to learn from one another by analyzing both the pitfalls and successes of the legislation of other states.\textsuperscript{111} With states serving as “laboratories of democracy,” the passage of time allows states to contribute to the collective understanding of genetic discrimination, resulting in expansive genetic anti-discrimination laws.\textsuperscript{112}

An incremental approach by states will hasten the acceptance of genetic discrimination as a pervasive issue at the federal level. Passing more effective legislation against genetic discrimination at the state level should be effectuated to give states the opportunity to respond to new forms of discrimination as they arise.\textsuperscript{113} While comprehensive federal legislation remains the ultimate goal, it can be achieved more easily once states have had time to appreciate the value of their legislation and experiment with implementation strategies.\textsuperscript{114} The present circumstances surrounding genetic antidiscrimination legislation are well-suited for an incremental approach because there is a lack of acceptance of its importance. This disparity in acceptance of genetic discrimination as a tangible issue is demonstrated by the majority of states not enacting any legislation to extend the limited protections offered by GINA.\textsuperscript{115}

\textsuperscript{110} Tucker, supra note 96 at 864 (if a state chooses to enact a novel law it “would do a service to the rest of the nation, as other states watch another state enact and implement such a law”).

\textsuperscript{111} Id. at 880 (“It has been widely recognized that the states’ ability to experiment with local solutions to public health problems is especially critical to the development of wise public health policy.”).

\textsuperscript{112} See id. at 879–80.

\textsuperscript{113} James E. Krier & Mark Brownstein, On Integrated Pollution Control, 22 ENVTL. L. 119, 126 (1992) (discussing how a comprehensive approach to solving environmental problems can lead to unrealistic reforms that ignore the “imperfections of the real world”). In the context of environmental policy, it is understood “that everything is interconnected, we fall into the logical fallacy of believing the only way to improve those interconnections is to deal with them all at once.” Id. at 125.

\textsuperscript{114} Lindblom, supra note 23, at 81 (before legislators can enact laws based on public preferences, there must be public discussion to ensure a majority preference accurately reflects the will of the public).

Just as the understanding of genetics took years to develop, a fully comprehensive framework of the genetic antidiscrimination law will not be immediately realized in “one fell regulatory swoop,” but rather it will be gradual as the circumstances in which genetic discrimination can occur come to fruition.\footnote{J.B. Ruhl & James Salzman, Climate Change, Dead Zones, and Massive Problems in the Administrative State: A Guide for Whittling Away, 98 CALIF. L. REV. 59, 62 (2010) (quoting Massachusetts v. Envtl. Prot. Agency, 549 U.S. 497, 524 (2007)). In the context of environmental regulation, instead of making drastic changes in regulation, environmental agencies “instead whittle away at them over time, refining their preferred approach as circumstances change and as they develop a more-nuanced understanding of how to best proceed.” \textit{Id.}} The path to effective and robust “[p]olicy does not move in leaps and bounds.”\footnote{Lindblom, supra note 23, at 84.} States are likely to disagree on approaches to understanding and tackling problems that new issues present.\footnote{\textit{Id.} at 85–86 (“[T]he incremental pattern of policy-making fits with the multiple pressure pattern. For when decisions are only incremental—closely related to known policies, it is easier for one group to anticipate the kind of moves another might make and easier too for it to make correction for injury already accomplished.”).} Because the states vary in the amount of urgency they place on expanding GINA’s protections, it is important to prioritize progress over flawless legislation, as “perfect must not become the enemy of the good.”\footnote{Krier & Brownstein, supra note 113, at 128.}

The expansion of regulation of genetic antidiscrimination legislation at the state level will allow for legislatures to develop novel policy change on a trial-and-error basis within the state.\footnote{Cf. Erwin Chemerinsky et al., Cooperative Federalism and Marijuana Regulation, 62 UCLA L. REV. 74, 78 (2015) (in the context of marijuana, “willing states [should be allowed] to experiment with novel regulatory approaches while leaving the federal prohibition intact for the remaining states”).} That state can then assess the success of the approach and modify it as necessary which could incline other states to adopt a similar law. Implementing laws governing genetic discrimination this way will also allow states to work through the inevitable limitations of human knowledge when working with a scientific moving target.\footnote{See Lindblom, supra note 23, at 85 (“given the limits on knowledge within which policy-makers are confined, simplifying by limiting the focus to small variations from present policy makes the most of available knowledge”).} Gradual change to the law allows states to focus on instances of genetic discrimination that are recognized by both scientists and society, which maximizes the benefit
of present awareness without attempting to blindly predict future areas of concern.\textsuperscript{122} After sufficient experimentation, the successes of the state-level legislative efforts could be integrated into a series of model laws that other states and the federal government could use when engaging in genetic antidiscrimination reform.\textsuperscript{123} The incremental approach thus prevents legislatures from prematurely enacting legislation by first educating the legislators on new areas of the law requiring massive policy reform.\textsuperscript{124} Although incremental change is gradual, in the sense that it is comprised of minor and unassuming steps, it has the potential to be a faster route to comprehensive genetic discrimination protection than slow but major legislative alterations.\textsuperscript{125}

Given the uncertainty surrounding the sectors of society that will definitively require protection, this approach allows each state to create legislation based on their citizens’ unique needs by evaluating the state’s unique political and social opinions to pinpoint areas of vulnerability.\textsuperscript{126} The various states developing their own comprehensive genetic nondiscrimination law will result in a body of legislation and public policies beneficial to all states.\textsuperscript{127} These policies will also be instrumental in the furtherance of protective legislation for states in the future. By having an array of legislators and policymakers creating tailored solutions in areas of genetic discrimination law states could render more effective legislation.

\begin{itemize}
\item \textsuperscript{122} Id.
\item \textsuperscript{123} See generally Deanna Barmakian, Uniform Laws and Model Acts, HARV. L. SCH. LIBR. (Nov. 4, 2020), https://guides.library.harvard.edu/law/unifmodelacts [https://perma.cc/F8FD-LBZ9] (illustrating the use of model laws as a basis of state legislation that can be adopted in whole or in part by a state).
\item \textsuperscript{124} Lindblom, supra note 23, at 85 (“Non-incremental policy proposals are therefore typically not only politically irrelevant but also unpredictable in their consequences.”).
\item \textsuperscript{125} See Charles E. Lindblom, Still Muddling, Not Yet Through, 39 PUB. ADMIN. REV. 517, 520 (1979) (in the context of political change, “[a] fast-moving sequence of small changes can more speedily accomplish a drastic alteration . . . than can an only infrequent major policy change”).
\item \textsuperscript{127} See Michael S. Sparer et al., Inching Toward Incrementalism: Federalism, Devolution, and Health Policy in the United States and the United Kingdom, 36 J. HEALTH POL’Y, POL’Y & L. 33, 42 (2011) (“[F]ederalism also creates legislative and regulatory ‘opportunity points’ that lead to a more expansive set of public policies.”).
\end{itemize}
B. Legal Models States Could Follow to Address Genetic Antidiscrimination

Governments in other countries have adopted various methods for creating legislation prohibiting genetic discrimination.128 Britain for example, has a moratorium in place on the use of genetic information in the context of insurance.129 A moratorium could be beneficial in the area of genetic discrimination because it is a temporary measure, and such impermanence allows for the moratorium to change as the understanding of genetic discrimination expands.130 Nonetheless, because it is not permanent, its use would still require the legislature to develop a plan for more enduring legal protections for victims of discrimination.131 Moratoriums could be implemented in areas identified as genetic discrimination trouble spots while the problem is still developing; which would avoid creating concrete legislation until the breadth and scope of the issue is understood. Returning to the example set forth earlier, consider a state that has identified insidious genetic discrimination in mortgage lending.132 The state may issue a moratorium prohibiting banks from using genetic information when considering the eligibility of borrowers for a ten-year period. During that time, lawmakers could develop a more complete understanding of what specific protections need to be afforded which would result in effective legislation tailored to protect against such discrimination. Passage of such legislation would then render the need for the moratorium obsolete.

A different approach is used in Albania, where genetic nondiscrimination is understood as a fundamental human right, and is directly addressed in Albanian human rights legislation.133 Though “[b]roadly formulated” to afford expansive protection from genetic discrimination, this approach is subject to the interpretation of the

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129 Joly et al., supra note 128, at 299 (describing the moratorium Britain has for the use of genetic information in providing health insurance policies).

130 Id. at 300.


132 See supra text accompanying note 109.

133 See Joly et al., supra note 128, at 300.
courts and “statutory exceptions.”\textsuperscript{134} Because genetic information is amalgamated with other broadly defined issues of human rights found in the legislation, its judicial interpretation is malleable. In one sense, judicial interpretation of the legislation could shore up ambiguities regarding when and how protection is afforded against genetic discrimination. In another sense, this malleability could also result in inadvertent lapses in justice if the legislation is not consistently applied. While broad legislation could be subject to the same shortfalls in GINA, the benefits of this approach are found in the nuances of judicial interpretation and application, which could fill any gaps left in situation-specific legislation on genetic discrimination.\textsuperscript{135} In any case, this is a model better suited for the final stages of genetic discrimination reform, which would occur after the substantive law governing genetic discrimination among the states is solidified or the uniform law is enacted at the federal level.

Finally, states could also use GINA as a template to adopt categorical prohibitions against specific patterns of genetic discrimination as they arise. Unlike the other options, this approach is already in use in California.\textsuperscript{136} This could be a beneficial approach, as it allows the state to tailor the genetic antidiscrimination law to its specific needs.\textsuperscript{137} For example, bans on genetic discrimination in education may exist in one state at a given time, while another state prohibits such discrimination in money lending. Of these three potential models for legislation that presented above, no single one can be expected to fit each state’s needs perfectly. The states may vary in the method of effectuating legislative protections against genetic discrimination, but the methods should be appropriate for the pursuit of steady progress toward extensive genetic antidiscrimination legislation.

\textsuperscript{134} \textit{Id.}

\textsuperscript{135} See Eduardo Ferrer Mac-Gregor, \textit{What Do We Mean When We Talk About Judicial Dialogue?: Reflections of a Judge of the Inter-American Court of Human Rights}, 30 HARV. HUM. RTS. J. 89, 90–91 (2017) (discussing how courts adapt to changing legal circumstances impacting human rights by looking to each other through a concept called “judicial dialogue”).

\textsuperscript{136} See generally CalGINA, ch. 261, 2011 Cal. Stat. 2774 (codified in scattered sections of the California Codes) (illustrating an example of an already enacted state level categorical ban on genetic discrimination in several contexts).

\textsuperscript{137} Joly et al., \textit{supra} note 128, at 300 (this approach could be referred to as “Sectoral prohibition”).
V. Conclusion

The infancy of genetic discrimination awareness in areas other than those afforded protection in GINA creates the perfect opportunity to create legislation before insidious discrimination can occur. Such legislation would propound the legislative intent of GINA, which was to preempt discrimination based on genetics before the practice could harm citizens. As science continues in its pursuit of understanding the human genome, problems implicated by the use of that information will persist. Over time, the understanding of the human genome will become more robust. As a result, legislation that protects against its misuse for discriminatory purposes should be equally comprehensive. The creation of legislation at the state level would allow states to learn from one another regarding the areas needing protections and how to effectuate those protections. This goal for effective genetic antidiscrimination law would be facilitated by making the changes in an incremental fashion to allow the issue of genetic discrimination to become clearer, thus preventing ineffective predictive federal legislation and protecting the rights of citizens in an ever-evolving modern society.