

# The Use of Genetic Information in Real Property Transactions

By Mark A. Rothstein and Laura Rothstein

**Mark A. Rothstein is Herbert F. Boehl Chair of Law and Medicine and Director, Institute for Bioethics, Health Policy and Law, University of Louisville School of Medicine. Laura Rothstein is Professor of Law and Distinguished University Scholar at the Louis D. Brandeis School of Law, University of Louisville.**

With the cost of genome sequencing continuing to decline and genomic information becoming more common in health records, it is foreseeable that entities with an economic interest in the future health status of individuals will be tempted to use predictive genetic information to assess the health risks of individuals who are parties to real property transactions. Thus, mortgage lenders, mortgage insurers, real estate sellers, senior living centers, retirement communities, and other entities involved in residential property might begin requiring genetic information as part of the application process. This article considers whether the use of genetic information in housing is lawful under federal and state laws. It also considers the ethical and policy issues raised by the acquisition and use of predictive genetic information in residential property transactions. A more extensive treatment of this topic by the authors can be found in Mark A. Rothstein & Laura Rothstein, *How Genetics Might Affect Real Property Rights*, 44 J.L. Med. & Ethics 216 (2016).

## **Genetic Factors in Adult-Onset and Late-Onset Disorders**

Recent advances in genetic research have identified hundreds of genes that play significant roles in the development of serious adult-onset or late-onset disorders. Some examples include genes associated with cardiovascular disease, heritable cardiomyopathies, and acute ischemic stroke. Various genes are associated with cancer risks, including breast cancer, colon cancer, and pancreatic cancer, as well as broader cancer syndromes. Another important group of gene-mediated illnesses are neurodegenerative disorders, which include Alzheimer's disease, Huntington's disease, Parkinson's disease, ataxias, and temporal dementia.

Alzheimer's disease is of special concern because it is relatively common, much-feared, for the most part untreatable, persists for an average of four-to-eight years from diagnosis to death, and requires significant skilled nursing care. Both early-onset Alzheimer's disease (approximately 5% of cases typically manifesting when the individual is in his or her forties or fifties) and late-onset Alzheimer's disease (manifesting at age 65 or older) are associated with several genetic risk factors. The cost of care for Alzheimer's disease and other forms of dementia is significant. According to a 2015 study, the five-year cost of caring for a person with dementia was approximately \$287,038, compared with \$175,136 for

patients with heart disease and \$173,383 for patients with cancer. On a population basis, in 2015 the total cost for care of patients with Alzheimer's disease in the United States was estimated to be \$226 billion.

### **Economic Incentives**

Residential property transactions are often significant financial undertakings, and therefore any party to such a transaction is likely to have an economic interest in the future health of the individuals involved. Thus, a bank, mortgage company, or other financial institution might be interested in learning whether an individual has a family history of or genetic predisposition to cancer, cardiovascular disease, Alzheimer's disease, Huntington's disease, Parkinson's disease, or other condition likely to affect the health and functioning of the individual in the future. Similarly, any of these conditions can be expected to increase the individual's health-care costs and, possibly, ability to pay a mortgage.

The aging of the American population increases the likelihood that various late-onset disorders with genetic components will have implications for individuals' residential property needs. In particular, as more baby boomers retire, there will be increasing demand for and interest in communities that allow residents to "age in place." Property developers targeting this market have recognized that a leading appeal is the active nature of these communities. Consequently, the operators of some of these communities, including condominiums or other cooperative housing, will want their businesses to attract individuals who are not only currently active but who are likely to remain mobile and cognitively intact. It is especially important that prospective residents will not witness substantial numbers of people using wheelchairs and walkers or needing assistance in their daily activities.

Those who provide housing for individuals age 65 and over have three primary motivations for learning about the health of the individuals seeking to move to retirement or phased-in assisted living. First is the cost of providing future services for individuals whose health is likely to decline more rapidly than normal. Second is the marketing issue, the "other resident preference" of providing housing communities that enhance the image of a vibrant lifestyle. Third is the ability of residents to continue paying their mortgage and residential fees.

The issue of individual solvency is relevant not only to retirees but also to younger individuals buying single family homes. Mortgage companies want to know that the borrower currently has and will continue to have the financial means to make payments for up to 30 years. This usually involves a consideration of current assets, income stream (typically reflected in employment), and a good credit rating. It is standard practice to seek this information on financing application forms and through credit checks. Such measures are generally viewed as lawful and ethically acceptable because of the financial institution's interest in loan repayment. Although it is not currently a standard practice, it is foreseeable that these institutions and those that market to certain population segments may begin to seek other information to predict the ability to pay as well as to maintain the desired image of the community.

## The Legal Landscape

Although a “compelled authorization” for disclosure of a residential property applicant’s health information, including genetic information, may seem distasteful, it is not clearly illegal. Obtaining and using predictive genetic information in residential property transactions is legally uncharted territory. The most likely context in which this may arise, especially relating to the risk of Alzheimer’s disease, is senior living facilities. Several statutes may be relevant.

### *Fair Housing Act*

The Fair Housing Act (FHA), 42 U.S.C. § 3601 et seq., was enacted in 1968 and originally prohibited discrimination in the sale or rental of housing only on the basis of race, color, religion, or national origin. An amendment in 1974 added the prohibition of discrimination based on sex. In 1988, the Fair Housing Amendments Act further prohibited discrimination on the basis of disability and familial status in the sale or rental of housing. It is probable that most of the housing transactions described above would be subject to its mandates, although there are some uncertainties about how nursing homes and similar housing arrangements would be treated. Entities subject to the FHA may not discriminate in the application for housing or in retaining eligibility for rental housing. Like other federal disability discrimination laws, the FHA prohibits discrimination based on “association” with a person with disabilities and also requires that reasonable accommodations be provided.

Most relevant to the application of the FHA to genetic information is the definition of “disability.” To be protected under the FHA, an individual must have a physical or mental impairment that substantially limits one or more major life activities, a record of having such impairment, or a record of being regarded as having such impairment. Because the focus of predictive assessment is future risk, the only possible category for coverage would be under the “regarded as” prong of the definition, and it is not clear whether a genetic predisposition would be included. The requirement that a condition be a “substantial” impairment is also somewhat unsettled in its application to a condition that *may* occur at some uncertain time in the future.

The FHA regulations prohibit an owner or landlord from inquiring into whether an applicant has a disability or its nature or severity. 28 C.F.R. § 36.302(c)(6). The only exceptions to this “no inquiry” rule involve inquiries into an applicant’s use of illegal drugs or ability to meet the requirements of tenancy or ownership. The language in the FHA regulation is based on the “pre-employment inquiries” provision of section 504 of the Rehabilitation Act, further discussed below.

The Equal Credit Opportunity Act prohibits discrimination in credit, including mortgages, based on race, color, religion, national origin, sex, marital status, age, or receipt of income from public assistance. 15 U.S.C. § 1691 et seq. Discrimination based on disability is not covered, but disability discrimination in mortgages is covered under the FHA.

There have been a few cases in this area. Complaints have been filed with the Department of Housing and Urban Development (HUD), which enforces the FHA, challenging several mortgage lending practices: requiring homebuyers with disabilities to submit a letter from their physician indicating the nature and severity of their disability and establishing that they would continue to receive disability

benefits for at least three years; submit a verification of disability from the Social Security Administration; or obtain medical documentation to qualify for an FHA loan. Although all of these cases, which were later settled, involved unlawful demands that the mortgage applicants demonstrate that they *had* disabilities, the reason for these demands was to demonstrate that they would have an income stream from which to make the loan payments. Thus, it is the same financial motivation that could prompt mortgage lenders to seek genetic information and deny a mortgage to individuals deemed likely to develop a disability.

It is possible that policies requiring mortgage applicants to submit genetic information could be viewed as having a disparate impact on individuals with disabilities. In *Texas Department of Housing & Community Affairs v. The Inclusive Communities Project*, 135 S. Ct. 2507 (2015), a race discrimination case, the Supreme Court held that disparate impact analysis is valid in housing discrimination cases under the FHA. Nevertheless, it may take years of case law development to clarify how this might work in housing situations involving genetic information.

#### ***Rehabilitation Act and Americans with Disabilities Act***

In 1973, Congress enacted the Rehabilitation Act, 29 U.S.C. § 791 et seq., the first major law prohibiting discrimination on the basis of disability. Section 504 prohibits discrimination in programs receiving federal financial assistance. Although this provision prohibits discrimination in federally supported housing, such as housing covered under section 8 of the Housing Act of 1937, very little attention has been given to housing discrimination under section 504.

In 1990, Congress expanded the programs subject to nondiscrimination on the basis of disability when it enacted the Americans with Disabilities Act (ADA), 42 U.S.C. § 12101 et seq. The three main titles of the ADA apply to employment, public accommodations (specifically not including most housing), and programs provided by state and local governments (including zoning).

Both section 504 and the ADA protect individuals with disabilities, defined the same way as in the FHA. And like the FHA, it is far from clear whether the “regarded as” or “associational” aspects of the definitions would extend to individuals (or their family members) with genetic predispositions to various impairments. The ADA was amended in 2008 to clarify that a broad reading of “disability” was intended by Congress, but it is questionable whether, for example, a mortgage company would run afoul of the ADA by requiring a mortgage applicant’s individual or family health information.

Under the ADA there is a well-developed body of regulatory guidance and case law in the employment setting about pre-employment inquiries and disabilities, including guidance on medical examinations and inquiries. A parallel and clear set of rules does not exist for housing. To date, the assumption undoubtedly has been that the sole focus is on the individual’s ability to pay. For any dense housing property, there may be additional reasons to ensure that the tenant’s behavior will not cause problems for the landlord or other tenants, but these inquiries are not generally about medical conditions. Although regulations promulgated by HUD permit questions to determine if an individual might pose a “direct threat” or cause harm to the property of others, general inquiries about an individual’s disabilities are not permitted.

Because some housing providers, such as nursing homes, provide care along with housing, their interests are broader and there may be legitimate reasons to know about the medical conditions of the residents. These reasons include ensuring the facility can provide the appropriate level of care and ensuring emergency health issues can be addressed promptly. Nevertheless, medical information should not be used to disqualify an individual from services that a facility is capable of providing merely because it “may require relatively more staff attention, or be perceived as distasteful by staff members or other residents.” E.M. Carlson, *Disability Discrimination in Long-Term Care: Using the Fair Housing Act to Prevent Illegal Screening in Admissions to Nursing Homes and Assisted Living Facilities*, 21 Notre Dame J. of L., Ethics & Pub. Pol’y 363, 371 (2007). The Nursing Home Reform Act provides heightened protection for individuals in nursing homes, but these protections do not extend to assisted living facilities.

### ***Genetic Information Nondiscrimination Act***

In 2008, Congress enacted the Genetic Information Nondiscrimination Act (GINA) to prohibit discrimination on the basis of genetic information in employment and health insurance. 42 U.S.C. § 2000ff. GINA defines “genetic information” as an individual’s genetic tests, the genetic tests of family members, and the manifestation of a disease or disorder in family members. GINA also prohibits employers from acquiring genetic information from the individual or a family member except in some specific situations, including inadvertent acquisition, voluntary and knowing provision of information as part of a wellness program, and in some specified employment settings.

GINA was not enacted to redress ongoing genetic discrimination in employment and health insurance. Especially for employment, little such discrimination was reported before the enactment of GINA or subsequently. Instead, Congress believed that individuals would be more willing to avail themselves of genetic testing and related services if there were established protections against genetic discrimination. In this sense, GINA was “preemptive.” GINA, however, has a limited scope; it does not apply to the use of genetic information in life insurance, disability insurance, or long-term care insurance.

GINA also does not apply to housing, but it is an important reference statute that might be valuable to consider in the context of possible new legislation prohibiting genetic discrimination in housing. In particular, GINA (1) indicates a congressional commitment to prevent discrimination based on genetic information, (2) prohibits the mere acquisition of genetic information, (3) defines genetic information to include the genetic tests and health histories of family members, and (4) already has served as a template for proposed and enacted expansions of genetic nondiscrimination laws at the state level.

### ***California Genetic Information Nondiscrimination Act***

Every state has a law prohibiting housing discrimination on the basis of disability, and 48 states have enacted one or more laws prohibiting genetic discrimination. As of 2016, however, only California had enacted legislation that specifically prohibits the use of genetic information to discriminate in housing. The California Genetic Information Nondiscrimination Act (CalGINA) amended the California Fair Employment and Housing Act (FEHA), the nation’s most comprehensive housing and employment discrimination law, to prohibit discrimination on the basis of genetic information. Cal. S.B. No. 559 (2011).

The remedies under California law greatly exceed those available under federal law. For example, under GINA damages for violations are capped at between \$50,000 and \$300,000, depending on the size of the defendant, whereas California law provides for unlimited damages. CalGINA took effect on January 1, 2012, and therefore it may still be too soon to assess the effectiveness or consequences of the law.

### **Ethical and Policy Issues**

Among the ethical issues implicated by the use of genetic information in real property transactions are autonomy, privacy, and justice. Autonomy is implicated by requiring individuals to undergo genetic testing in which they may learn information that they would not like to know. Genetic information bears directly on the risks of family members, and for some disorders, such as Alzheimer's disease, very little can be done to prevent or treat the condition. Furthermore, decisions about where to live are fundamental to individual autonomy. As long as an individual meets the financial and other reasonable qualification standards, property owners, operators of residential facilities, mortgage lenders, and other parties with an interest in residential property should be prohibited from disqualifying the individual based on predictive genetic information.

Another important interest is the privacy of individuals in their genetic information. Although the easiest way of getting genetic information would be to obtain the results of prior genetic tests, in the absence of new legislation it probably would be lawful to require that individuals undergo genetic testing as part of a real estate application. Health privacy legislation at the federal (HIPAA Privacy Rule) and state levels is extremely weak. See Health Insurance Portability and Accountability Act of 1996, 42 U.S.C. § 300gg et seq. Of particular concern, once health information leaves the control of a covered entity under HIPAA (for example, a health-care provider), there are virtually no prohibitions on the subsequent uses and disclosures of the information.

Finally, as indicated above, there is the potential use of genetic predisposition to Alzheimer's disease in screening applicants for senior living facilities. Excluding individuals based on a genetically increased risk of Alzheimer's disease violates the ethical principle of justice. Many individuals at increased risk will never become symptomatic. Furthermore, individuals at all stages of their lives, but especially at the end, should be treated with dignity and respect. Basing real property eligibility on predictive health information is inconsistent with the nation's commitment to justice and equality of opportunity.

### **Conclusion**

Predictive genetic information has the potential to profoundly affect individual rights in real property. For many individuals, their residential property is the largest financial asset they will own in their lives; for virtually everyone, the use and enjoyment of their residence vitally affects their quality of life. The prediction of late-onset, gene-mediated dementias and other serious impairments is likely to be one of the first widespread applications of genetic information in the realm of real property. To date, the ethical, legal, and social implications of genetics and real property have not been analyzed in detail, despite their implicating fundamental individual and societal concerns about autonomy, privacy, and justice. Legislation at the federal or state level should be enacted to prohibit real property decisions based on genetic information and to prohibit requiring individuals to provide genetic information as a condition of purchasing, leasing, financing, or other property-related transactions. n