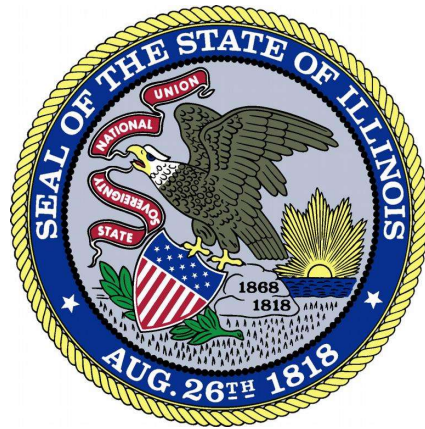


Governor's Office of Management and Budget

Alexis Sturm

Director



Illinois Regulatory Sunset Act Review of The Genetic Counselor Licensing Act

January 29, 2024

**To the Honorable JB Pritzker
Governor of Illinois**

Governor Pritzker:

The Governor's Office of Management and Budget ("GOMB"), in compliance with the requirements set forth in the Regulatory Sunset Act (5 ILCS 80), has conducted a review of the Genetic Counselor Licensing Act (225 ILCS 135), which is scheduled to be repealed on January 1, 2025. As a result of this review, GOMB makes the following recommendation:

The Genetic Counselor Licensing Act should be extended without modification.

GOMB's examination of this Act was conducted considering the factors set out in Sections 6 and 7 of the Regulatory Sunset Act. The following study and analysis details the criteria and data utilized to arrive at the above recommendation.

Very sincerely and respectfully,

Alexis Sturm
Director
Governor's Office of Management and Budget

GOMB Regulatory Sunset Act Report: Genetic Counselor Licensing Act

The State of Illinois, acting through the Department of Financial and Professional Regulation (IDFPR), licenses the profession of genetic counseling pursuant to the Genetic Counselor Licensing Act. The phrase “genetic counseling” is defined in that Act to refer to “the provision of services, which may include the ordering of genetic tests, to individuals, couples, groups, families, and organizations by . . . appropriately trained individuals to address physical and psychological issues associated with the occurrence or risk of occurrence or recurrence of a genetic disorder, birth defect, disease, or potentially inherited or genetically influenced condition in an individual or family.” See 225 ILCS 135/10. Genetic counselors are persons licensed under the Act to provide genetic counseling services.

1. License Count and Fee Structure

IDFPR reports the following number of genetic counselor licenses issued in each of the indicated fiscal years:

Table 1: Total Number of Licensees FY18 – FY22

License Type	FY18	FY19	FY20	FY21	FY22
Genetic Counselor	54	60	75	103	77

As of September 29, 2023, IDFPR states that there are 609 active licenses for genetic counselors in Illinois, 1 license application in progress, 9 expired licenses, 10 inactive licenses, and 221 licenses that have not been renewed.

To obtain licensure in Illinois applicants must demonstrate, among other things, that they meet one of the following criteria:

1. Verification that the applicant has successfully completed a master’s degree in genetic counseling from an American Board of Genetic Counseling (ABGC) or an American Board of Medical Genetics (ABMG) accredited training program or an equivalent program approved by the ABGC or the ABMG;
2. Verification that the applicant is a physician licensed to practice medicine in all of its branches; or
3. Verification of a doctoral degree and successful completion of an ABMG accredited medical genetics training program or an equivalent program approved by the ABMG.

Applicants must also demonstrate that they have successfully completed the examination administered by the ABGC or the ABMG.

Applicants may obtain a temporary license if they have met the licensure requirements set out above, other than the completion of the examination, and also provide verification of admission to a certifying examination administered by the ABGC, ABMG, or either of their successor agencies.

As provided in IDFPR’s rules, a temporary license expires 24 months from the date of issuance and may only be renewed if the examination is not given during the 24-month period. If the holder of a temporary license fails to take the next available examination or fails to successfully complete the next available examination, the temporary license is void and the individual must cease practicing. If the

temporary license holder fails to stop practicing it is considered unlicensed practice and the person is subject to individual discipline in accordance with Section 25 of the Genetic Counselor Licensing Act.

Should a person attempt to practice without a license, Section 25 of the Genetic Counselor Licensing Act authorizes IDFPR to impose civil penalties, providing in pertinent part:

Any person who practices, offers to practice, attempts to practice, or holds himself or herself out to practice as a genetic counselor without being licensed or exempt under this Act shall, in addition to any other penalty provided by law, pay a civil penalty to the Department in an amount not to exceed \$10,000 for each offense, as determined by the Department. Civil penalty shall be assessed by the Department after a hearing is held in accordance with the provisions set forth in this Act regarding the provision of a hearing for the discipline of a licensee.

Genetic Counselors have the following licensure fee structure:

Table 2: Genetic Counselor Licensure Fee Structure

License Type	Fee Amount
Application for license (first time application or endorsement)	\$150
Temporary license	\$50
Annual license renewal	\$75

2. Necessity of License

Section 20 of the Genetic Counselor Licensing Act (225 ILCS 135/20) addresses those activities that constitute the practice of genetic counseling and provides:

[N]o person shall, without a valid license as a genetic counselor issued by the Department (i) in any manner hold himself or herself out to the public as a genetic counselor under this Act; (ii) use in connection with his or her name or place of business the title "genetic counselor", "licensed genetic counselor", "gene counselor", "genetic consultant", or "genetic associate" or any words, letters, abbreviations, or insignia indicating or implying a person has met the qualifications for or has the license issued under this Act; or (iii) offer to render or render to individuals, corporations, or the public genetic counseling services if the words "genetic counselor" or "licensed genetic counselor" are used to describe the person offering to render or rendering them, or "genetic counseling" is used to describe the services rendered or offered to be rendered.

...

No association or partnership shall practice genetic counseling unless every member, partner, and employee of the association or partnership who practices genetic counseling or who renders genetic counseling services holds a valid license issued under this Act. No license shall be issued to a corporation, the stated purpose of which includes or which practices or which holds itself out as available to practice genetic counseling, unless it is organized under the Professional Service Corporation Act.

In addition, Section 20 discusses the limitations placed on genetic counselors and states:

(d) Nothing in this Act shall be construed as permitting persons licensed as genetic counselors to engage in any manner in the practice of medicine in all its branches as defined by law in this State.

(e) Nothing in this Act shall be construed to authorize a licensed genetic counselor to diagnose or treat any genetic or other disease or condition.

(f) When, in the course of providing genetic counseling services to any person, a genetic counselor licensed under this Act finds any indication of a disease or condition that in his or her professional judgment requires professional service outside the scope of practice as defined in this Act, he or she shall refer that person to a physician licensed to practice medicine in all of its branches.

The Act's language emphasizes the General Assembly's interest in regulating this profession. The Act affirms that regulated acts by an unlicensed individual or an organization representing themselves to the public as genetic counselors may result in public harm. The purpose of the service performed by a genetic counselor is to identify and deliver accurate genetic information to individuals and families, to assist the families in adjusting to the implications of their diagnoses and to provide the appropriate level of counseling on core components of the client's genetic health. The decisions made and the subsequent medical care sought based on the services of the genetic counselor may have the most profound effects on the client's mental and physical health, wellbeing, and ultimately, survival if the genetic defect or disease detected is of a life-threatening nature.

IDFPR asserts that licensure of this profession is necessary to protect the public's health and safety by ensuring that genetic counselors have the knowledge, experience, and competency needed to provide such services to individuals, families, and health care providers. The need for quality genetic counselor training and licensure helps safeguard the public by ensuring appropriate tests are ordered, test results are interpreted correctly, and an accurate understanding of the meaning of the test results is conveyed to individuals and families.

3. Equity Concerns

The General Assembly included several exemptions in the Act to ensure that the regulatory scheme had minimal impact on other individuals engaged in similar or related activities and to ensure that applicants for licensure and medical professionals were not unduly burdened by the Act. Section 15 of the Genetic Counselor Licensing Act (225 ILCS 135/15) states:

(a) This Act does not prohibit any persons legally regulated in this State by any other Act from engaging in the practice for which they are authorized as long as they do not represent themselves by the title of "genetic counselor" or "licensed genetic counselor". This Act does not prohibit the practice of nonregulated professions whose practitioners are engaged in the delivery of human services as long as these practitioners do not represent themselves as or use the title of "genetic counselor" or "licensed genetic counselor".

(b) Nothing in this Act shall be construed to limit the activities and services of (i) a student, intern, resident, or fellow in genetic counseling or genetics seeking to fulfill educational requirements in order to qualify for a license under this Act if these activities and services constitute a part of the student's supervised course of study or (ii)

an individual seeking to fulfill the post-degree experience requirements in order to qualify for licensing under this Act, as long as the activities and services are supervised by a qualified supervisor. A student, intern, resident, or fellow must be designated by the title "intern", "resident", "fellow", or any other designation of trainee status. Nothing contained in this subsection shall be construed to permit students, interns, residents, or fellows to offer their services as genetic counselors or geneticists to any other person and to accept remuneration for such genetic counseling services, except as specifically provided in this subsection or subsection (c).

(c) Corporations, partnerships, and associations may employ students, interns, or post-degree candidates seeking to fulfill educational requirements or the professional experience requirements needed to qualify for a license under this Act if their activities and services constitute a part of the student's supervised course of study or post-degree professional experience requirements. Nothing in this subsection shall prohibit a corporation, partnership, or association from contracting with a licensed health care professional to provide services that they are licensed to provide.

(d) Nothing in this Act shall prevent the employment, by a genetic counselor, person, association, partnership, or corporation furnishing genetic counseling services for remuneration, of persons not licensed as genetic counselors under this Act to perform services in various capacities as needed, if these persons are not in any manner held out to the public or do not hold themselves out to the public by any title or designation stating or implying that they are genetic counselors.

(e) Nothing in this Act shall be construed to limit the services of a person, not licensed under the provisions of this Act, in the employ of a federal, State, county, or municipal agency or other political subdivision or not-for-profit corporation providing human services if (i) the services are a part of the duties in his or her salaried position, (ii) the services are performed solely on behalf of his or her employer, and (iii) that person does not in any manner represent himself or herself as or use the title of "genetic counselor" or "licensed genetic counselor".

(f) Duly recognized members of any religious organization shall not be restricted from functioning in their ministerial capacity provided they do not represent themselves as being genetic counselors or as providing genetic counseling.

(g) Nothing in this Act shall be construed to require or prohibit any hospital, clinic, home health agency, hospice, or other entity that provides health care to employ or to contract with a person licensed under this Act to provide genetic counseling services.

(h) Nothing in this Act shall be construed to prevent any licensed social worker, licensed clinical social worker, licensed clinical psychologist, licensed professional counselor, or licensed clinical professional counselor from practicing professional counseling as long as that person is not in any manner held out to the public as a "genetic counselor" or "licensed genetic counselor" or does not hold out his or her services as being genetic counseling.

(i) Nothing in this Act shall be construed to limit the practice of a person not licensed under this Act who is a physician licensed to practice medicine in all of its branches under the Medical Practice Act of 1987 or intern, fellow, or resident from using the title "genetic counselor" or any other title tending to indicate they are a genetic counselor.

(j) Nothing in the Act shall prohibit a visiting ABGC or ABMG certified genetic counselor from outside the State working as a consultant, or organizations from outside the State employing ABGC or ABMG certified genetic counselors providing occasional

services, who are not licensed under this Act, from engaging in the practice of genetic counseling subject to the stated circumstances and limitations defined by rule.

GOMB's study and analysis concludes that educational/training opportunities certified by the American Board of Genetic Counseling (ABGC) in Illinois are limited. The University of Illinois at Chicago (UIC) and Northwestern University are the only institutions that offer a master's degree program in Genetic Counseling in Illinois. At the same time, of the 33 programs certified by the American Board of Medical Genetics (ABMG), none are in Illinois and only 7 are in the Midwest. Accordingly, the programs necessary for licensure are physically located only in the Northeast section of the state. The lack of geographic diversity, as well as the tuition requirements for the two programs in Illinois pose significant barriers to entry for individuals located downstate, as well as to minority and economically disadvantaged students in general who must pay tuition, fees, room, and board to engage in study.¹

Additionally, fees charged by ABGC and ABMG for certification and examination,² combined with the license fees required under the statute may be an impediment to economically disadvantaged students seeking to enter this field. Further study of these issues and coordination with industry groups and educational institutions with an eye toward broadening opportunity is recommended.

Agency efforts to comply with enabling laws

IDFPR did not recommend any changes for this Act, based on best practices research. To the best of GOMB's knowledge, IDFPR is in compliance with the provisions of the Act.

Pending Legislation

GOMB's study and analysis of this area, however, resulted in the location of amendatory legislation affecting the Act. House Bill 4282 of the 103rd General Assembly, which, among other things, extends the repeal date of the Act to January 1, 2030, indicating an interest on the part of some members of the General Assembly to keep the Act in place.

Stakeholder Feedback and Protocols for Genetic Counselor Licensure

IDFPR did not report having received comments from professional organizations or other interested parties regarding the impact of IDFPR's rules or its administrative decisions related to enforcement of the licensing program. Further, IDFPR is not aware of any public feedback.

Public Outreach

IDFPR provides multiple avenues for members of the public to contact the Department with comments or concerns about programs it regulates or the Department's rules governing its programs. Although IDFPR conducts public outreach efforts through social media and other external-facing means, IDFPR is unaware of any ongoing or recent full-scale media or advertising campaigns solely dedicated to this profession.

Public Complaint Resolution

¹For 2023-2024, in-state tuition for the University of Illinois at Chicago's Graduate School is a minimum of \$12,470 per year for full time study plus fees of \$4,898. [Cost of Attendance \(COA\) | Student Financial Aid and Scholarships | University of Illinois Chicago \(uic.edu\)](#). Tuition for 2023-2024 for Northwestern University's Graduate School is \$21,550 per quarter for full time study plus applicable fees. [The Graduate School: Student Finance - Northwestern University](#).

²ABGC first time examination fees are \$900. For repeat licensure applicants, the ABGC fee is \$800. ABMG fees are \$1,000.

IDFPR has not received any formal public complaints regarding the Genetic Counseling licensure program in the last five years. Further, IDFPR does not report on its efficiency to resolve public complaints. There is no report of IDFPR inefficiencies resolving public complaints related to the Genetic Counselor Licensing Act.

Disciplinary Action

The Genetic Counselor Licensing Act provides for disciplinary action against genetic counselors if problems arise in their practice, during the provision of their services, or for other specified events (e.g., admission under the Mental Health and Developmental Disabilities Code, income tax delinquency related matters, and child support delinquency).

Further, the National Society of Genetic Counselors (NSGC) has adopted codes of ethics and practice standards required of all providers who obtain certifications. The American Board of Genetic Counseling, Inc. also utilizes the NSGC codes and standards and maintains a list of practice-based principles that members must follow. Effective January 1, 2024, NSGC is implementing new disciplinary procedures to strengthen accountability within the profession. Illinois law requires that genetic counselors licensed in the state adhere to practice level competencies, which include professionalism, encouraging ethical behavior in the profession, maintenance of appropriate boundaries, and demonstrating interest and participation in activities that have the purpose of promoting access to correctly performed genetic services.

Conclusion

The Genetic Counselor Licensing Act governs the licensure of genetic counseling in the State of Illinois. The absence of licensing criteria for genetic counselors would pose a significant and direct harm to the safety and welfare of the public. The lack of regulation would eliminate the ethical standards that protect consumers and genetic counseling services. Genetic counseling is a relatively new profession and in recent years there has been an advent of generic genetic tests made available to the public. State laws govern the coordination of assessments, the delivery of accurate information to families, the provision of assistance to families who are adjusting to the implications of their diagnosis, and the application of standards to ensure that genetic information is used appropriately in the delivery of medical care. Without regulation, genetic counseling would have insufficient standards that could result in threats to public health. Therefore, the health and safety of the public is put at risk without proper training, licensing, and oversight of genetic counseling. Although there are concerns about the equitable access to certified training programs in the State of Illinois, to protect the consumer and the profession, it is imperative that Illinois utilize licensing and operational requirements for genetic counseling.

The absence of regulation of this industry would pose a significant and direct harm to the welfare of the public. Current evidence does not suggest that the imposition of the state regulatory standards is such a burden as to outweigh the benefits to the health, safety, and welfare of the people of Illinois in continuing the licensure and regulation of this profession. Consequently, the Act is necessary and appropriate to ensure the health, safety, and welfare of the people of Illinois.

The Genetic Counselor Licensing Act should be continued to promote and enhance the safety and welfare of the public, without placing burden on licensees and commerce.