Georgia Occupational Regulation Review Council Minutes

July 12, 2017

Call to Order: The first meeting of the Georgia Occupational Regulation Review Council for the consideration of House Bill 636, related to the proposed licensure of genetic counselors, was held on Wednesday, July 12, 2017, in room 450 of the Georgia State Capitol Building. The meeting convened at 2:00 p.m. The council members in attendance and constituting a quorum were:

Present: Anna Wrigley Miller (OPB), Ashley Sellers (Ag), Amber Carter (filling for Wes Robinson, DNR), Daniel Regenstein (DOR), Tim Fleming (SOS), Sidney Barrett (DPH), and Rep. Sharon Cooper

Absent: Sen. Renee Unterman and Alan Skelton (SAO)

Staff Attendees: Meaghan Ryan

Presenters:

• Jenee' Burke (J Burke Strategies, LLC), Katie Lang (Genetic Counselor, Board Certified, Hereditary Cancer Program Coordinator at Northside Hospital), and Andrea Paal (Board Certified Genetic Counselor, works for Quest Diagnostics)

New Business:

I. Call to Order

The Chair of the council, Anna Wrigley Miller, called the meeting to order and discussed the goal of the meeting. Members would have a discussion with the group in attendance, who were presenting information related to the bill proposal and regulation.

II. Introduction of Members, GORRC Process and Schedule

Anna Wrigley Miller started off the meeting with a quick overview of the GORRC process, which is outlined in O.C.G.A. 43-1A. HB 636 was referred to the council by Rep. Cooper's committee. The chairman noted that the criteria for the council to use to evaluate the bill is narrowly tailored and urged everyone to keep this criteria in mind. The goal of the council is to recommend through a report whether or not the proposed business or profession should be regulated.

III. Overview of House Bill 636

Meaghan Ryan gave a brief summary of the bill. She noted that The Georgia Composite Medical Board would regulate the licensure. The license would require a fee and would be effective for 2 years. The bill defines a genetic counselor and what groups are excluded from licensure.

IV. Scheduled Discussion

Jenee' Burke, Katie Lang and Andrea Paal presented on why they think genetic counseling should be licensed in Georgia. Jenee' Burke stated that 23 other states license the profession and 3 others states are in the process of regulating (MI, SC, and FL).

Katie Lang:

The goal of genetic counseling is to help patients understand and adapt to the genetic component of disease. There are some diseases that are hereditary. Genetic disorders are unique in that they are lifelong. Not everyone with these particular genetics will have cancer, but may have the chance later on in life. Empowering and educating people are a large part of the job. They have a lot of training in medical genetic testing including choosing the correct testing to order. Genetics have become very lucrative, and genetic counselors are able to vet the tests ordered due to their training. A doctor usually refers a patient to the counselor to evaluate them for cancer risk. The genetic counselors order the test, receive the results and disclose the results. They spend 90 minutes with every patient before the test preparing patients for the results. Results can have multiple impacts including health insurance coverage. Many people don't realize the implications of testing. Disclosing the actual results of the tests are also a large part of the counseling. Genetic Counselors are able to give the context of what the results mean.

The Chair asked if there was a specific case that brought up licensing now. Katie Lang said genetics is exploding and almost coming routine in oncology. They need people to understand that they are the experts in this realm. As technology increases, the barriers for testing decreases. The result doesn't matter if you don't know how to interpret it.

Sidney Barrett mentioned that the presenting group estimate 77 genetic counselors eligible for licensure in Georgia. He was curious who outside of the 77 are providing this information and who are they providing it to. Katie Lang wanted to clarify they are not seeking to limit who can order genetic testing. They want to be the resource for this and that no one can call themselves a genetic counselor without the training they have. Sidney Barrett asked if there is anyone outside of the medical community that are ordering and interpreting results to citizens. Katie Lang said that some people who are social workers, secretaries, etc. are calling out results. Andrea Paal said that there is a social worker with a personal history with breast cancer is providing this service with no medical training. She said it is hard to imagine that a patient is receiving the same level of care with a social worker than with a genetic counselor. There are several cases of harm in the packet provided to the council that showcase what can go wrong with incorrect interpretation.

When counseling, genetic counselors are non-direct when discussing options. They let them know what their options are and refer them back to their doctor to act on those options. Andrea Paal added there is a psychosocial aspect that they are trained in so that patients know what to do with the information once they have it. Counselors can also guide people to talk to someone long term about their results.

Rep. Cooper said that she knows that RNs do not receive training in this, and she didn't get training. She asked if this meant people are giving out the information from the tests. Are the doctors telling you that they have training in this? Katie Lang said she thinks that people don't have malicious intent. Their patients want this service and the doctors aren't sure of the resources available to them. Rep. Cooper

said that we may have become so used to the ease of ordering tests. Katie Lang said that there is no one to tell the doctor's what they are doing wrong. Additionally, it has become very easy to order 90 genes at once to evaluate a person's risk, but no one really needs that many with the proper counseling. Some companies don't require patients to meet the criteria to be tested and will waste money on useless tests.

Sidney Barrett said this leads back to his original concern with people ordering unnecessary tests. He asked if we need to be protecting patients from people calling themselves genetic counselors or saying you shouldn't be doing genetic counseling at all without a license. The applicant group said that the way things are heading, the insurance companies are intervening on the ordering of testing by limiting who can order tests. For them, having the title protection is more important. Licensure may increase access to genetic testing. Most genetic counselors in the state are concentrated in the metro area. They are developing telemedicine for genetic counseling, but in order to be reimbursed for telemedicine, you have to be licensed. Northside Hospital is providing it or free at this time. Telemedicine is a great benefit of licensure. Genetic counseling is perfect for telemedicine because no physical contact is needed. Sidney Barrett said that all public health clinic (in every county) has telemedicine. Andrea Paal said there is a tremendous market for genetic testing in rural areas.

Sidney Barrett asked who the licensing entity is in other states. It is the same board that regulates physicians, in Georgia it would be the Composite Medical Board. Sidney Barrett said we can rely on them to handle scope of practice issues. Katie Lang said that we can take advantage of lessons learned from other states. Due to scope of practice, it seems like the only real overlap between genetic counselors and doctors is when talking about options to handle the results given. Katie Lang said that they tell patients to go back to their doctor or are able to recommend a specialized doctor for surgery via referral. Sidney Barrett asked if the cost of genetic testing is expected to go any lower. Andrea Paal said that it has been gotten about as low as it can go due to materials, time, and labor.

Ashley Sellers asked if licensure in other states has resulted in more genetic counselors. Katie Lang said she isn't sure if it is the licensure or the fact that the field is exploding. There are other things drawing people into the field. 29% growth is expected in the field from 2014 to 2024. Compared to other fields, that is considered extraordinary growth. Sidney Barrett asked if Emory is the only place in Georgia to get a masters in genetic counseling. It is rumored that Morehouse may add a program. Florida is adding two programs. It is self-limiting in the fact that you need genetic counselors to teach genetic counselors. Jenee' Burke said that she can provide a full list of programs.

Chair Miller asked to clarify testing needed for licensure. The board certification is the only test needed and Georgia would recognize that. Continuing education would be required by the state. During the rule making the fees will be decided.

Rep Cooper asked about the continuing education units. The Georgia Association of Genetic Counselors have a meeting each year to provide CEUs. The meeting is approved by the national board to count as CEUs. Georgia is seen as a leader in education. Rep Cooper asked if the national organization is developing educational opportunities online. They are developing online opportunities as well as approving various conferences to count for CEUs.

Sidney Barrett asked if they are comfortable with the language of the bill. The applicant group said they are and that the bill is similar to the Kentucky GC bill.

V. Open Public Comment

There was no parties interesting in commenting.

VI. Adjourn

Anna Wrigley Miller said that judging by the feeling in the room, the committee will put together a recommendation for regulating genetic counselors. There were two more meetings planned, but it seems as if it is not needed. OPB will develop the report, and if there is a need for another meeting, we will have one on the date reserved (August 9th). The meeting adjourned at 3:00 p.m.