

Genetic Counselor Training Program Capacities and Needs
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DR. McCABE: Thank you very much.

Our next speaker is Robin Bennett, who is past president of the National Society of Genetic Counselors.

MS. BENNETT: Thank you for the opportunity to present to you today. There is a formal copy of this report in your packet and also on the back table. So I'm just going to go through some of the highlights.

We were asked last June by the Secretary's Advisory Committee on Genetics, Health, and Society to give a report that develops a plan for gathering data on what is needed to increase the number, diversity, and quality of training of genetic counselors. This is a specific focus of the SACGHS under their general priorities to supply diversity, certification, and education and training of the health care workforce in genetics, and this discussion pertains to master's level-trained genetic counselors. Master's level-trained genetic counselors have extensive training in human genetics and counseling skills.

You also asked us to try to put some dollar amounts with this, and so I will be putting some of that in this report.

The methods that we used were we collected this information from July to October of 2003. We did a survey in September of the Association of Genetic Counseling Program Directors, and we also did an interview and met with the American Board of Genetic Counseling in September. We also had a consultation with Judy Cooksey, and you've heard about her 2000 workforce study and we reviewed that also.

We did try to look at the answer of how do you spell success in having enough genetic counselors, and I did try to do some investigation into programs in Canada and the U.K. to see if programs with a more uniform health care plan, if they had actually addressed this issue, but I couldn't find any evidence that that had been looked at in that way.

We also have a lot of information from the National Society of Genetic Counselors database. Our membership is 2,100 individuals all over the world, but I focused mainly on the training in the U.S., given the scope of this committee, and we believe that NSGC, 85 percent of practicing genetic counselors are members of this organization.

We also worked with our Industry Special Interest Group to see some ideas of where the technology was taking the field of genetic counseling. The NSGC, every two years we do a professional status survey. So that provided a lot of the information for this report, and then our Executive Office provided us information on our membership.

So this report is a brief review of the field of genetic counseling right now, with the focus on the U.S. population, the current status of the genetic counseling training programs, suggestions for expanding the existing programs while maintaining a high quality, and suggestions for developing new programs. We also were asked to focus on enhancing the diversity of the genetic

counseling profession.

This report does not look at the workforce issues of other genetic specialists. You've heard a little bit about genetic nursing and the medical geneticists.

It's also not an independent report. It's through the National Society of Genetic Counselors. We did look into the cost of maybe having a report that would be independent and we estimated that if you wanted such a report it would probably cost anywhere between \$90,000 and \$150,000.

This represents the geographic distribution of the genetic counseling programs in the United States. There are currently 25 genetic counseling programs in the United States. There are three in Canada. Canadian citizens have priority in those programs, and so few genetic counselors are trained in Canadian programs, although genetic counselors trained in Canadian programs serve in the U.S. workforce.

There are 11 programs, represented by the green dots, that are in consideration, and the "RNPS" stands for "Recognized New Program Status." So they haven't been accredited by the American Board of Genetic Counseling yet, but they are anticipating that they will become full programs. There are two states, California and Utah, that have licensure for genetic counselors, and there are several that are pending that.

I think that there will always be some dearth of programs in certain parts of the country because these tend to be associated with academic medical centers. So for example, in Washington State, we are the only academic medical center for Washington, Alaska, Montana, Idaho, and Wyoming. So unless some of those kinds of things change, I think there are challenges to having programs everywhere.

The American Board of Genetic Counseling is the official accrediting body of the genetic counselors. As I mentioned, there are 25 programs. You can see that, unlike in some of the other genetic specialties, there has been a steady increase in the number of genetic counselors. Because of this and because of the licensure of genetic counselors that is pending, the American Board of Genetic Counseling will now be offering the cycle every two years, instead of every three years, and hopefully that will continue to see the same advance.

The accreditation of programs, the genetic counseling training involves 27 areas of competency within four critical domains. The critical domains are communication, critical thinking, interpersonal counseling and psychosocial assessment, and professional ethics and values. There is considerable didactic course work involving human and medical genetics, cytogenetics, developmental biology, embryology, teratology, statistics, quantitative and qualitative research, counseling theory, interviewing techniques, communication skills, ethics, and public policy.

The time-intensive part of this training is the field work of over 800 hours per student. There is also a commitment to having teaching experience in all the students and as part of the accreditation process, and also all the programs have a research component. The average program length is about two academic years.

It's hard to predict the demand for genetic counseling. It's hard to predict what people are going to want when tests become available. For example, in Huntington's disease, when people were polled how many people wanted to be tested, up to 79 percent of people intended to be tested, but worldwide only 9 to 20 percent of people have chosen to be tested. So it's hard to say when people are asked what would you do if this theoretically existed and then predict their behavior

when that becomes available.

As a profession, genetic counselors have been very able to meet the demands of the field. For example, in 1994, there were only 10 percent of the profession practicing in cancer genetics, and in 2002 over 42 percent of the profession is practicing in cancer genetics. I think that the broad base of training in genetics makes this group particularly adaptable to changes in the market.

We also have adapted to increasing our patient load without necessarily getting more resources to do so. So between 2000 and 2002, there has been a 66 percent increase in the number of patients seen. So you can see, as compared to what was given for the medical geneticists, about 572 is the average annual patient volume for a genetic counselor.

I can say in my own practice at the University of Washington, in 1996 we saw maybe 26 people for cancer genetic counseling. This year, we'll see over 400. So there is a big demand for services that's increasing.

I think that the demand for genetic counseling, there is always going to be specialties that want to refer to a genetic counselor. So some people are going to become competent. Some professionals and others are going to want to make that referral.

It's also very much tied up with billing and reimbursement, and the best example I have is from a letter I actually got from a surgeon that he sent to his insurance company that was for this patient.

It says, "To whom it may concern: I am responding to your letter refusing genetic consultation on" this patient "and suggesting that we do pedigrees, et cetera, on her. You are forgetting who you are writing to. I am a surgeon. Remember, we are not cognitive professionals. I don't know how to do pedigrees. The only people that do pedigrees are genetic counselors and dog breeders. Since she is not a dog, I thought the geneticist would be the best fit, and thus my request."

It continues, "Perhaps you will still refuse our small and humble request. Then, in keeping with 'Frank and Earnest,' we will send her to you for genetic counseling," and you can see the comic: "You want a second opinion? Call your insurance company."

The demand for genetic counseling may not be that you see a genetic counselor office in every block, like you might see an attorney or a real estate agent, but I think that the number of jobs that are listed on the National Society of Genetic Counselors job postings shows that over 75 percent of genetic counselors find a job within one month of graduation, and in Myriad Genetics in 1996 -- this is a major cancer genetic counseling service -- they had one genetic counselor in 1996 and they have 33 employed now. There has been a steady rise in the number of jobs. The last column, it's not a full year yet, so there were about 143 jobs posted so far this year.

Genetic counselors are not only clinicians, but they serve as a resource for the community. For example, 71 percent of genetic counselors serve on an advisory board of a consumer support group. They also are very involved in organizing conferences and workshops, particularly for health professionals, and also for consumers.

Genetic counselors are also a major workforce in terms of teaching. You can see that 77 percent were involved in teaching medical students and 34 percent taught other health professionals. They also are involved in many of the nursing curriculums, with over 70 percent teaching nurses, and there has been a specific focus on physician assistants and social workers, probably because of some of the things you heard in some of the earlier talks about their initiatives.

In the current genetic counseling programs, most of them are in academic medical centers. There are six that are at private schools. The rest are public. The average size is 16, with the range being six to eight to 46 students for the total enrollment over the two years. Estimates are that 550 students applied for genetic counseling programs last year. The majority of these are women and also Caucasian. These people are very qualified applicants with high GPAs and GREs.

So when we get down to the limits of the genetic counseling training programs, the biggest limit that overall was expressed was quality field placements for that 800 hours of field placement, and if a program loses a field placement, they have to often reduce the number of people enrolled in their program.

There is also an enormous volunteer effort that goes into genetic counseling training. There are over 400 hours per year for the average supervisor if they do four rotations per student per year. The rotations are usually six to eight weeks or so, and they also do a lot of teaching that is uncompensated. So the lack of funding for programs and limited scholarship opportunities are the biggest gaps that were reported.

The annual cost to train a genetic counseling student, again, this is just based on talking to the program directors. It wasn't going to their actual centers, their programs, but they range from \$25,000 to \$50,000, with the average being \$30,000. The higher range tended to be the private institutions over the public institutions. There are a lot of physical resources and in-kind contributions that are also given that aren't accounted for in this number.

So here's what we are proposing. We have sort of a two-pronged approach to increase the number of genetic counselors in the workforce and the capacity of training programs. That was to look at the existing training programs and funding of new programs.

So the biggest thing that the existing programs need is additional training sites, and there also are very limited student stipends for getting people to -- if we were going to expand the number of sites, they would have to be often out of town, and so if there was a student stipend of maybe \$3,000 per year to cover housing and travel expenses to get to these off-site rotations, that would be a big help.

Also, the supervisors, as I've already said, are giving a lot of volunteer time, and so if you're thinking about 100 hours of rotation per supervisor, if you were looking at a \$25 an hour base pay, which is based on the average salary from the professional status survey and wouldn't account for people with a lot of experience in genetic counseling, some of the more experienced supervisors, that would be about \$2,600 per student or, if you were looking at it in FTE mode, that would be \$10,400.

Also, there is a need for additional faculty. There is currently limited funding for clinical and research supervision, and this limits the number of students that can be admitted. We feel that adding additional faculty would also benefit educating other health professionals because you could have joint appointments in physical therapy, social work, nursing, whatever.

So an FTE for a genetic counselor would be \$80,000 to \$100,000, including benefits, and for a medical director/geneticist it would be \$150,000 to \$175,000.

To have some sort of training grants for students, similar to doctoral candidates in many other types of allied health professionals, would also help the existing programs, and you could

consider tying this support to limited obligation to practice in an underserved area.

We felt that a diversity scholarship was an acute need of the profession, and some sort of a student stipend to cover books at about \$5,000 per student would be another approach to enhance these programs.

If you were going to increase new programs, we suggested three to four years of start-up funds, and you might require the institution to have a matching fund. So this is the estimated cost for a new program. I talked about a genetic counselor program director of \$100,000. An M.D.-Ph.D. geneticist, \$175,000. Program administrator, supervisor stipends. If you were going to count the average size of a program as being 16, so there would be probably 32 placement rotations, that may be a few individuals, and then continuing education and resources, and then the diversity scholarships that I mentioned for the existing programs.

One way to increase the existing programs and to enhance new programs would be to do more teaching through webcasting. So you could have Dr. McCabe teach all of the genetic counseling students in the country at one time if you were going to do webcasting. This would help eliminate faculty time and expense.

It would also perhaps enhance student communication with journal club and case conferences, so that programs that are very small may have that benefit of conversing with other students in other programs. The cost of that, I didn't have a way of estimating that, but many medical institutions do have this kind of equipment and the charges are really for the land lines and the technical support.

The benefits of targeting funding for genetic counseling training are many, and I think if you look on Appendix A at the end of your packet, we ask the programs if we had funding -- we didn't say how much -- how big could you grow your program? And they all were willing to expand with the exception of maybe one or two programs. Most programs could expand at least 50 percent and some could actually double in size if you could deal with the supervision sites, the training site issues.

We already have at least five programs that have talked to the American Board of Genetic Counseling that are waiting to exist and I had 11 on that actual map. So there are certainly plenty of new programs that are just waiting to exist.

Having more training for genetic counseling would increase the diversity of the field if we had funding to get students who couldn't afford to come to the genetic counseling programs as they're offered now. We would get more diversity, and having more diversity gives more role models for clients to see genetic counselors besides white Caucasian women. There would also be increased access to genetic counselors by other health professionals for teaching.

So I think the genetic counseling workforce is an enthusiastic workforce willing to do clinical work, teaching, public policy, work with genetic industry, and I think that even though there may be a limited number at this time, I think it's a good bang for the buck in terms of the money.

I just wanted to end by saying that the NSGC is available as a resource for future workforce assessments or to provide expertise in developing initiatives to support genetic counseling training programs and increasing the genetic counseling workforce, and the American Board of Genetic Counseling and the Association of Genetic Counseling Program Directors also expressed their dedication to providing data for such initiatives. Thank you for your time.

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TRANSCRIPT