

Workforce Issues
Judith Benkendorf, M.S.

DR. McGRATH: Ann, thank you.

Our final speaker is Judith Benkendorf with the American College of Medical Genetics. She is going to offer a perspective on the workforce issues. Thank you.

MS. BENKENDORF: Great. Good morning, and thank you. It is a pleasure to be here. Since I am the last speaker and you have been sitting for a long time, I thought I would give you my bottom line first. This is a talk where I'm going to tell you what you already know: the genetics work force is very small, unequally distributed geographically, and not representative of the broad diversity in the U.S. population.

I think this is especially striking in light of the latest announcements in the last couple of weeks from the consumer genomics service organizations, or as they call their new product, consumer genomics services, by 23 MedicoGenetics and Navigenics.

So, what does our genetics work force look like. I will just tell you that these data come from the American Board of Medical Genetics, the American Board of Genetic Counseling, and also from our workforce study. Both of the publications from that study are in your packets.

There are approximately 4,700 individuals who hold certificates in a medical genetics profession. About half of them are genetic counselors, and the other half are M.D.s and Ph.D.s certified by the American Board of Medical Genetics. Remember not all these individuals are still alive, and not all of them live in the United States and work in the United States, so we are probably a little bit smaller than these numbers.

We are not very diverse. The M.D.s and Ph.D.s are a little bit better. Thirteen percent identify with minority populations, the predominant group being Asian.

As Angela mentioned, the genetic counselors are the fastest growing cohort. We are about half of the work force, but still only about 6 percent are men, 9 percent representing with minority communities. Again, here is the African American communities.

If you look at the U.S. population of about 103 million people, that is one genetic counselor for 127,000 U.S. population. Sitting here in the District of Columbia, I'm told there is one lawyer for every 17 of us. So we are slightly outnumbered.

What do the M.D. geneticists look like. We are less than 0.02 of all the physicians in the United States. We estimate there are about 1,100 active clinical genetics physicians in the United States. In a recent survey done through the American Board of Medical Genetics by the College, we learned that these individuals spend only 45 percent of their time seeing genetic patients. So we have to divide that number out. So we have one full-time equivalent for every about 560,000 people, or 1.8 clinical geneticists per million population.

We get a lot of phone calls. "How many geneticists should there be?" The Royal College of Physicians estimates about one FTE for each 250,000 people as the idea. Again, based on the U.S. population as the Census Bureau posted it in July, we need 1,200 full-time equivalent medical geneticists, but we are not quite halfway there.

This is just a graph of certification trends. Because the board cycle is now compressed to two years, I estimated what this would be if it was a three-year cycle. Maybe it was a little bit generous, but it shows you the trends. It is the genetic counselors that are going up the fastest. I think the clinical geneticists have a little bit of increase, and molecular geneticists, but the rest of it is pretty flat and we are no longer offering the Ph.D. exam after this cycle.

So the medical genetics work force situation is critical. I put that in red. We can't emphasize it enough. The services work force is not expected to meet patient care demand within the next few years. There is a serious mismatch between the explosion of knowledge and the work force size. Young physicians are not entering our field. You can hear this cry. I go to a number of AAMC-related work force meetings, and they are all saying young physicians are not entering our field. This is not going to help by the fact that there is an emerging national physician shortage coming down the pike.

Many states, at least 17 according to the Work Force Study, have been identified as having an inadequate number of geneticists to meet the demand right now, and the metabolic geneticists are in the most critical need.

The issues of how geneticists work is also a factor. Melissa Fries mentioned this, and I will mention it again from the Banbury II conference, and we are going to address it also in Banbury III. Geneticists have to take care of patients across the life span, from womb to tomb. No more of this saying "I only take patients with this age and this disease." As Bruce Korf says, you are not a neurology unit that says if you have epilepsy go to the medical center across the street. We can no longer afford to do that.

A picture is worth a thousand words. A researcher from Harvard just called me last week and wanted the zip code of all of the active clinical geneticists in the ACMG database. This is only 509 people, but the lighter the state, the fewer the geneticists. You see some states with gray, Idaho, West Virginia, Wyoming, and Alaska have no M.D. geneticists. Obviously, the darker blue have a large population and also more geneticists.

There is a bit of misnomer. Maryland always comes up very high, but remember our clinical genetics friends at the NIH are not doing clinical practice, so that is a bit skewed.

So, what is the status of our metabolic geneticists. On one hand, we are expanding newborn screening and the other Secretary's Advisory Committee is even entertaining the idea of putting more diseases in the panel. Ten thousand new affected individuals who are going to need lifelong chronic disease management and treatment are coming into the system every year. We counted them yesterday; of the 258 people who hold biochemical genetics certificates, exactly 200 of them also have an M.D. degree.

This is the group that is least able to expand services, and this is based on 2003 data from the Work Force Study. Their practices are nearly full. Twenty percent were expected to retire in the next five years, and there is only one more year left in those next five years.

Several states were unable to expand their newborn screening panels to meet the uniform requirement due to a shortage of metabolic physicians. So this is serious.

The approaches to remedying this problem need to be multi-pronged. One thing that I think has been said, maybe not bluntly enough, is there is no federal funding for training medical geneticists. Any time ACMG is asked to provide technical advice on legislation, we ask

them to put in funding. In fact, S.1858, which is the newborn screening legislation, was just reported out of the Senate HELP Committee and it does have money in there for education.

We also have one ACMG-F through our foundation, an industry-sponsored M.D. fellowship position for a clinical geneticist. Finally, our board has approved, together with ACMG, the creation of our first clinical geneticist subspecialization. This is the medical biochemical geneticist. So there is now going to be subspecialization in clinical genetics, and I think we are going to be seeing more of that.

As Melissa said, the Banbury conference on the evolving role of the geneticist first talked about the fact that we need to recruit and how can we improve training and recruitment. At the end of that conference, they realized that when different people around the room, the stakeholders, said medical geneticists and the practice of medical genetics, they weren't all talking about the same thing.

So we brought people together again with broad representation back to Banbury Center a year and a half ago to define the domain of medical genetics practice. How can you write curricula if you don't know what you are training people to do. Can we agree on some principles that underpin this practice.

This document is about to be published in Genetics and Medicine. It will underpin Banbury III. Mike wants me to make sure I tell people that it is not going to be at Banbury, but we still call it Banbury III anyway. This is where we are going to actually develop curriculum and medical genetics training for genetics.

I'm not going to go through all of these principles, but they do come from a pre-published document. I will just highlight a couple of those as follows.

The first one is obviously that we are dedicated to improving the health of individuals, families, and communities, and that we see patients across the life span and for conditions involving all organ systems. We also, obviously, have a public health interest, and we need to be nimble. We need to respond to the rapid pace of discovery with new educational and training and practice paradigms.

A little bit about how we practice. Obviously, we are, and remain, a team-based sport. We are interested in the translation of new technologies into health care, monitoring outcomes and also patient management, and this includes becoming medical homes and coordinating care as appropriate. This goes on and on about the need to expand the training, and many of these concepts have already been said today.

I think I will end with the last slide to say, how are we going to get to where we need to be from here. I'm from the American College of Medical Genetics, and we are here to help.

Muin, in response to your comment, we now have a tagline, which is "Translating Genes into Health." We are working on a branding campaign. We do have a public relations and media advisor working with us, and I think you are going to be seeing the roll-out of really trying to position us more in the eyes of the public as the individuals who actually translate genes and genetic information into health and into health care.

Hunt Willard, in his presidential address in 2001, when he was the ASHG president, talked about opening the tent. We have to open the medical genetics training tent to expand the work force.

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We have to expand our number of joint training programs, such as pediatrics, medical genetics, internal medicine medical genetics, pathology medical genetics, neurology medical genetics, and the list goes on, as well as some of these subspecialty certificates.

Again, realigning the training efforts to involve common disease, which is often very, very complex. It is not simple genetics and does involve the teaching of gene-environment interactions and health care throughout the life span.

We have to be cognizant of how genetics services will be distributed based on complexity. There is a role for genetics in primary care. There is a role for genetics in specialty care. There is also a role for the medical geneticist.

We also, I think, need to keep our eyes on the ball of the consumer genetics and personalized medicine movement. I'm pleased to say that several of these companies have approached the American College of Medical Genetics looking for ways to use us as resources.

So to position the profession, we want to be able to provide adequate clinical support to the range of service settings, and there are not enough of us to go around. We are already the educators of medical students, but we are supposed to be the educators of everyone else. We are going to see all these patients.

We are going to reach out to rural areas with our new technologies. We are doing a lot to push telemedicine through our National Coordinating Center and the Regional Genetics and Newborn Screening Collaborative.

We are looking at new training modalities. We are integrating our point of care and decision support tools into the electronic medical record. So some of us need to be writing these tools and developing them and promoting them and testing and evaluating them to make sure that they are working.

Am I getting tired going through this list. But we need to, obviously, anticipate future needs and get ahead of the eight-ball and, as I said, develop tools and new practice paradigms so that the work force can grow. It is going to take a multi-pronged approach and a multidisciplinary one.

I think I will stop there. Thank you.