

Overview of Session
Barbara Burns McGrath, R.N., Ph.D.

DR. McGRATH: Good morning. For the next couple of hours we are going to be talking about genetics education and training of professionals. This is actually the most fun part of the Committee deliberations, I think, where we get to sit back and really learn from the people who are the top in their field in these things and have put together their ideas in a smaller packet of information for us. So I think this morning is going to be very interesting.

It is an area we are revisiting in a roundtable format just as we did a few years ago, and I think the reason is that it is one of those topics that requires or calls for periodic review or a second look. This is one of those.

I think it is really an important or very appropriate agenda for this Committee. If we think about the pipeline that extends from genetic discovery to utilization, sitting right in the middle are the various health professionals that we are going to be talking about today. All of us here who do research or craft policy know that our great ideas can just pile up and get stuck right there if these people don't implement them appropriately.

So to use a word that has gotten more familiar in our vocabulary in the last year or so, these people that we are going to be talking about today, they are the deciders. They are the ones that move all of our discoveries forward.

As a social mandate, we want these professionals to be knowledgeable about genetic principles so they can, for instance, decide which genetic test is the appropriate one to order and then be able to interpret the results correctly.

We want them to understand complex ethical issues and then make decisions about difficult problems like whether or not to disclose results to asymptomatic children.

We also want them to attend to larger societal issues, like thinking about what is the best way to ensure equitable access to appropriate genetic services to under- or uninsured people in our country, and then to think through is this the best way to eliminate health disparities in our country.

So regulations are written and clinical protocols are created to offer guidance. That was a lot of what we did yesterday. But these folks are the ones that first have to learn about all these suggestions that we have for them, agree that they have relevance in their own professional worlds, and then make their own decisions about how to implement them.

So let me quickly review how we got to today's session and put it into some sort of context. A Reed just mentioned, the need to explore issues around education and training have been part of the strategic plan since its inception. I'm going to talk about how it fits into the Oversight Report in just a minute.

But first, back in 2003, there was a very similar roundtable held that resulted in the 2004 resolution that was presented to the Secretary of Health. Some of you here were involved in that effort. The entire resolution is in Tab 4, but briefly, there were nine resolutions, and I'm going to go over those. They are summarized here a little bit.

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The first one is to incorporate in HHS programs and policies into the philosophy that genetic information is an integral part of all health care, then to facilitate this integration by collaborating with state, federal, and private organizations. This one also called for sharing of case studies and practice models specifically.

Another one was to promote and support initiatives that integrate genetics and genomics in education and training of health professionals. This resolution also referred to promoting family history information and supported point-of-care models. It also linked the Health Information Technology Initiative to it.

Another one was to encourage and support programs that promote diversity and cultural competency of the healthcare work force. This included issues associated with disability rights.

Work with relevant organizations to incorporate knowledge of genetics and genomics in accreditation licensure and certification processes. This one was suggesting using the accreditation process as a driver for educational programs.

Support federal programs for faculty training and clinical application-based education models, particularly those that include ELSI issues. This was an emphasis on ELSI issues in terms of educating the work force.

Promoting consumer education and supporting K-12 education programs. The K-12 issue here was intended to establish a pipeline for a future diverse work force.

As you can see, these are rather broad and general. After that committee submitted the resolutions, the SACGHS moved on to other priority areas related to its charter, and you heard a lot about those yesterday.

So in the intervening years after 2004, between 2004 and now, things have changed. It is time for the Committee to take another look. To that end, we have asked key people in the area to come and give their perspectives today. We are doing that now because, as you read the oversight report, it is clear that health professionals have a role to play here, and that is highlighted particularly in Chapter 6 of that report. We hope that this session may contribute to that final report.

Because of this link to the Oversight Report, this session was convened over a very short period of time and some of the folks here had a very short turnaround, in weeks, not months -- for some people it was like one week -- to prepare for this, so we appreciate the effort that they all gave to being here today.

These are the members of the steering committee. Many of them will be presenting today. I would especially like to thank Cathy Fomous of the Committee staff, who actively participated in the decisions and coordinated all the efforts. Cathy, it has really been a pleasure working with you on this.

These are the disciplines that are represented. Some people wore more than one hat. You will see that we do not have consumer representation here. Boundaries were placed to limit today's sessions to issues around professional development. The issue of scientific or genetic literacy is of course very timely and important and probably deserves its own forum.

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Similarly, we are not including a review of federal efforts during this session. We are addressing education and training very broadly, including specialists and non-specialists, and consider the continuum from basic education, advanced specialization, to continuing education of those in the work force.

After reviewing the 2004 session and a discussion with the steering committee, these are the topics that were identified to guide today's discussion. The first one we are asking everyone to talk about is addressing the issue of professional education and training from their perspective. The second one is the whole issue of diverse work force. What is happening in their area, any progress made, any new plans for improving that.

What are the emerging issues in the field, and in particular, gene environment interactions that are very complex. We are interested about what efforts are being made to educate people about that, and emphasize its role in clinical care or public health.

Who are the emerging stakeholders that we should be thinking about in the future when we are thinking about education and training. Then, genetic family history is an area that is heavily marketed as a very important tool in individual and population-based care. Practitioners are being urged to integrate it into their practices, and we are just interested to know how it is going. There has been a lot of activity around it, but we haven't heard a lot of results yet.

Then, as I mentioned earlier, we are asking everyone to consider the 2004 resolution as well as the 2007 Oversight Report.

The purpose of this session is to provide an opportunity, as Reed said, to listen and have some conversation with the experts who are gathered here. It is a great opportunity to do that.

The format is that each person will have 15 minutes to present their views, followed by five minutes of questions that can be directed at that particular speaker. We are going to be holding to that time very carefully. There was going to be a break at 10:30. There will be a break someplace in here with the new change, but at some point we will get a break.

Then, after all six presentations are finished, we will then turn to the invited discussants for their comments. Then we will have a little more than a half or so for general discussion.

The goal here today is to decide on next steps. This is something that we are going to decide as a group at the very end, and for that end we would like you to consider two questions while you listen to all of this. The first one, does the topic of genetic education and training continue to be an area of concern consistent with the SACGHS's charter. Second, if so, what elements are most important for us to address considering the scope of our charter.

So, thank you. I'm looking forward to your participation in this. We will start with our first speaker, Mr. Joe McInerney. I will let each speaker introduce themselves and describe what group they are with.

Thank you, Joe.