

Cluster 3: Genetics Education and Training
Barbara Burns McGrath, R.N., Ph.D.

DR. WISE: Thank you very much, Steve. We will move on to Cluster No. 3.

DR. McGRATH: Thank you. We have a suggestion that it is about the money or it is about the value. I'm going to suggest it is about the knowledge.

This topic about the need for basic genetic education and ongoing training resurfaces a lot. It was one of the initial priority-setting topics within the initial SAC. Then it rose again to high on the list of the data gathering we did with this group and the public comment. I have a feeling it is going to continue to resurface every five to 10 years as long as we are talking about these things.

There are reasons for that. We started a task force based on some other priority setting in November of 2007. You have heard a fair amount about our activities, so I will make this fairly brief since the Committee has heard about this a lot. But in terms of addressing the need at the priority-setting, I will review it a little bit.

In our committee, we decided to identify three groups to focus on for our short-term goals, and those are the needs of health professionals with and without expertise in genetics, the needs of public health providers, and the needs of patients and consumers. Each of those groups are represented by task force heads. They are collecting data on those in different ways.

In terms of background, why is this important. The data continues to come in that clinicians and consumers are being increasingly expected to have greater and more sophisticated knowledge, but the education perhaps isn't keeping up with that.

The policy questions. What we would like to do, and what we are planning on doing, is looking at the initiatives and programs that are out there. There are quite a few. We are at this point collecting data on all the ones that are being implemented and being planned and trying to evaluate whether those are adequate. If any of those are particularly good, we will see if we can use those as models so we don't have to reinvent the wheel.

With that, what is the role of the federal government in all of this. There is no shortage of information about education, but we need to keep our eye on the idea of how can HHS help with education and training. We will then look to see the role of the federal government in this.

An important area is what role can the federal government take in promoting and supporting diversity and cultural competency of the healthcare professionals and the work force. This is a really important area. We would like to use this as one way to deal with the Healthy People 2010 recommendations that we address health disparities in the country by looking at it through the angle of increasing the diversity of the healthcare work force through the angle of genetics education and training. This is perhaps a newer area that we are going to be looking at.

The other one is the whole notion of accreditation, licensure, and certification. That is a role that the government can play. We will look at how that might be improved or changed or what is happening in that area.

The next couple policy questions are dealing with patients and consumers. Of course, we all know that there is lots more information reaching patients and consumers that isn't necessarily being filtered. We would like to broaden that by looking at various experts who are working in

SACGHS Meeting Transcript
December 2, 2008

the area of communication and patient education by looking a little deeper at the work of academic researchers as well as clinician educators and lay health educators, as well as what industry is doing to address their interest in educating consumers.

I think we heard a lot about this at our last meeting. We saw a lot of the promotional material that is reaching consumers directly about genetic services. We would like to take a look at that. Some of it is very sophisticated. It is being used not just for marketing but it is educating consumers as well as health professionals. That might be an unintended purpose of it, but we might as well look at that and see if there is something to be gained from that or if we have something to learn from that.

Along with that, is there a role for FDA to be involved in monitoring that in terms of some of the things that the Oversight Committee brought up in the last report.

We have some action steps. There are some very short-term ones. At the last phone conference it was suggested that we really could sit down very briefly and quickly with FDA to see whether it is under their purview to deal with issues around the medical device promotional materials that we are seeing, as well as talking with industry about establishing voluntary standards for promotional materials in terms of their educational properties.

The more longer-term ones. All three of the groups are very busy working on gathering data, doing interviews, collecting surveys, and collecting existing materials. We will have a report ready for public comments this coming summer, the summer of 2009, with hopes that the final report will be finished in the year 2010.

As I started off by saying, we have identified three groups: health providers, public health practitioners, and patients and consumers. There are other groups that continue to emerge as being involved that have needs for education and training. We have a list there. The next round may be to look at some of those people as the next level, not the first line of contact but the next layer of people who are involved in the decision-making around genetics to see what their education and training needs are.

I think that's it. Thank you.

DR. WISE: Yes, please.

DR. KIRCHNER: Thank you very much for a nice report. I'm just wondering what interaction you envision between the educational responsibilities and recommendations you have made and the work of Task Force No. 2. It seems to me that the two ought to be very much related. It is just as important to notify people about tests that have not been validated and therefore perhaps should not be used, as about tests that have already been proven to have a valid relationship to risk factors and therefore potential intervention.

DR. McGRATH: Absolutely. I would consider that the whole notion of clinical utility needs to be shared with providers and practitioners as well as consumers and patients. Absolutely. Thank you.

DR. WILLIAMS: If I could just add to that, as Steve mentioned in his report, the EGAPP working group and then the associated stakeholders group of EGAPP, one of their tasks is to try and actually disseminate the information, whether it is positive or negative, relating to that utility. So it does seem to be a natural point of reinforcement.

SACGHS Meeting Transcript
December 2, 2008

DR. WISE: Part of the discussion that I hope follows the cluster presentations will be to look for connections across the clusters as much as individual ideas or suggestions within each cluster. I think it is going to be very important for us to look for commonalities and ways to create coherent linkages. In fact, reclustered of the clusters may in fact be the most helpful thing we can do.

Other comments? I just want to thank Barbara for all your work with the task force. It has been truly impressive and fits very well among the highest priorities that were identified by the Committee.