Minutes Thursday, March 10, 2011

Morning Session - Called at 9:00 a.m.

1. Welcome/Meeting Opening
   Welcome words by Co-chairs

2. Update on Sponsored Research Committee by Dr. Thomas Pearson
   Dr. Pearson informed the TF of the following:
   • The Sponsored Research Committee has been meeting via video conference.
   • The committee is ready as a consortium to submit joint proposals. Resource material about the four institutions is being collected.
   • Many of the proposals have a short turnaround, particularly with the federal initiatives.
   • The committee has discussed looking for applications now and the process of which institution will be the leader. The most likely to get the proposal funded should be the leader.
   • The next stage is to actually prepare to apply to one or two. We need to understand that the process is a learning curve.
   • There is one application looking at science and life science training for high school students, maybe this is something Gallaudet and RIT would have interest in.
   • There are also a number of applications for individuals at the post-doctoral training level for laboratory fellowships.
   • Dr. Pearson final words were to comment that he is pleased with the progress of the Task Force, and that he was sure Jim DeCaro and Alan Hurwitz are all anxious, as he is, to hear what the Task Force will come up with.

After presentation, two people were officially introduced:

• Dr. Georgia Sadler from the University of California in San Diego is joining the group. She was in DC to attend the last meeting day in January that was canceled.
• Carol Fisher is a visitor from Rochester General Health System, New York. She is a member of the Sponsored Research Committee and will join TF meetings occasionally to learn more about the TF work.
3. **Update on Community Health Center Project by Irene Leigh and Gloria Wilder**

- Main goal of this initiative is to increase the number of deaf and hard of hearing service providers and set up a clinic for deaf and hard of hearing patients in the Washington D.C. area.
- There are many providers in Rochester and in Baltimore, but DC has nothing.
- Gloria Wilder came up with a wonderful idea to join a large community agency (Bread for the City) on the planning grant to set up those services. There was a meeting with the director of this agency to discuss this probability.
- The plan is to set up part time trained interpreters, nurses, and doctors who are willing to serve deaf and hard of hearing patients and who can communicate with them directly. This service would be provided for a few hours one day a week.
- Bread for the City is a long standing community agency in Washington, D.C. They provide free health care, transitional services, a clothing bank, and a food bank. They were in northwest Washington, D.C. and expanded recently with $3 million from the government. Their next goal is to go to Northeast D.C. where Gallaudet University is located. What a better idea than to put together Bread for the City’s service experience and Gallaudet’s communication experience.
- Washington, D.C. has a shortage of speech therapy and audiology services. There is a two-year waiting list for speech therapy. Think of a child waiting two years! That is a big difference in gathering speech skills or not. We are hoping to expand together.

4. **Updates by Jim DeCaro**

Jim DeCaro was asked to join the TF meeting and explain the intended audience for the Task Force Report.

**First Report**

- The first work product will come in June. The recommendations in this interim report should be steps that could be undertaken by the four partner participants/institutions that will make a significant difference. The June report is not intended to have overarching and wide recommendations; that is expected to come with the final product, which is the culmination of the work of the Task Force.
- The short term recommendations could be as simple as initiate contact with certain organizations in preparation for potential partnerships and collaborations.
- The idea of the four institutions as they set up the Task Force and committed funding was that the first report would not be confidential, but would not have widespread distribution. It would be the recommendations to the four institutions for what could be done in a relatively short time.
Final Report

- The final White Paper would become a nationally distributed report that would come from the four institutions. It is expected that the recommendations would go beyond the four institutions.
- The four institutions are important key players, but there are many other critical constituents that would join in partnership.
- The recommendations of the final report will become a nationally distributed product that will have the name of the four institutions on it. As we move into the future, the hope is that these recommendations would establish something bigger than the four institutions.
- We are not developing this report for Congress. But Congress will be an audience. Not for the White House, but White House Health Policy will certainly be an audience.
- The focus of the White Paper should be much broader in terms of TF thinking, maybe even a little wild. Think outside the box for some things that may require a stretch. That could require 8-10-12 years, but be thinking about those things in the final report.

Summary:

- The first report’s primary audience is the four institutions.
  - First report should be not too long nor too verbose, but should include recommendations that will anticipate the final document.
  - Recommendations will be put in for the four institutions to start to network.
  - The second report will have strong recommendations, such as to establish a consortium that will continue on after the Task Force finishes its work.

Questions/Comments/Answers:

C: My comment is on something you said that was really important. If our first report is about what these institutions do, that implies we need to know a lot about them. That is a key implication of what you said.

A: We have people here from University of Rochester and Gallaudet who have good knowledge about their institutions, and when the Task Force will need information you will ask them. If the Task Force does not have that knowledge available it will difficult to make recommendations.

Q: Related to that, does the University of Rochester Medical Center include University of Rochester generally? And does RIT include NTID as a partner?

A: I can’t speak for University of Rochester. But NTID is at RIT. That is why we had Dick come in. And now Kristen is running our premed program here at RIT. The answer is, from my perspective, yes. That means NTID and RIT. Fifty percent of our students are mainstreamed into the greater university. At the University of Rochester I would hope you would receive the same answer.
C: I want to say I thought what you said was helpful to get me focused on what our next steps are and being action oriented. I think that is important. As many ideas as we have around the table, it is also important we focus on the health careers portion. There may be new technology the Task Force is interested in because it allows someone to go into a career in health care that they may not have had access to before. Or it improves their performance in the career they have now due to new technology.

A: My concern is access technology. The ideas we come up with have to have universal design for direct implications for access in the health care field.

C: There was an article in the *New York Times* about technology and health care, and how we can really focus on the technology. But it is also important to focus on the human component, and not neglect the social interaction component as well.

C: Think about yourself as a change agent. There are different stages. One is getting people interested to participate. Then start to change conventions over time. Be careful you don’t over promise or provide expectations that are not in our reach. We want to talk up what we are doing, get people interested, but don’t get them expecting we will have the solutions. That will come over time. What we will give them are approaches to dealing with challenges that exist. We won’t necessarily have intervention, but rather approaches that are developed. Think about that piece. Don’t over sell.

Q: How can we stay involved once the TF is officially finished in 2012?

A: That is what I meant when I said that there needs to continue to be a national consortium. That could include members of the Task Force.

5. **Review of the Two-Day Agenda and Meeting Goals**
   - Draft of the June Paper will be discussed and feedback collected to be used by the Writing Subcommittee in preparing the next draft document.
   - Short-term goals will be discussed in general as a whole TF, and then subcommittees will break out to revise the short-term recommendations.
   - Tomorrow’s meeting will be dedicated to the long-term goals.

   - June Interim Draft Report that was sent to Task Force members previous to the meeting was reviewed.
   - A summary of all June Interim Draft Report’s categories and subcategories recommended were displayed to be discussed.
   - Attendants analyze if the categories and subcategories represent what the June Short-term Report should have.
RECOMMENDATIONS TO ADD TO THE JUNE REPORT

1. Insert in the narrative what is currently happening out there as part of the short-term recommendations.

2. Add to the information dissemination section, a speaker’s event on health care careers and the reasons for having more deaf and hard of hearing people enter those fields.


4. Include a “List of Best Practices” - people need a place to contact other people who have experienced the same problems and who are doing well.
   - Could be mentioned in the report and add an Appendix on that information.
   - List agencies and departments instead of personal contact information to avoid conflicts.
   - Have an online central information area where employers and anyone could access best practices. Who will be responsible to maintain the site?
   - Networking website where all institutions will provide links to where best practices are highlighted.
   - Consider television ads and public service announcements, such as the U of R’s commercial – “medicine of the highest order.” We could have a deaf nurse featured so people can realize that deaf nurses are possible and might even be a draw for potential patients.

5. Have a list of schools that have admitted deaf students into their health care programs as guidance.
   - List of schools with health care programs and graduates from those programs.
   - List of Pre-college outreach programs
   - Information related to health care careers.
   - Information for parents and educators related to opportunities for deaf and hard of hearing children.
   - Success stories and information to educators.
   - Identification of institutions and highlighting what they have done.

6. Develop and send recommendations to the four partnering institutions to see which institution can do what. Ask them to respond back to the Task Force.

7. Marketing?
7. Instructions for breakout session
- Change, modify, revise the Interim June Report Draft
- Pay attention to your areas and information dissemination.
- Add the suggestions previously discussed:
  o Educational Training Program - add or separate out the employer training program.
  o Accessibility/Technology – clarify recommendations
  o Policy/Research – discuss the suggested short-term recommendations the group came up with: stay with them or change them?

Afternoon Session: 1:00 p.m.

1. Subcommittees Reports
   • Educational Curricula and Training Program Subcommittee
     Two important points to highlight:
     o One is we were very concerned in quite a few areas that emphasized science and not allied health. Whenever it is possible in the document to include the wide range of opportunities for students, we need to do that.
     o How to provide information to people that is helpful but not restricted or filtered. We struggled with for example, how to classify jobs according to interaction or communication needs. We decided that it is not fair to provide a list of jobs that have few communication requirements. That would be a very filtered list.
     Decisions:
     o Start with the top 50 jobs in the health care field and describe in brief statements what is required for communication in the job. That leaves it to the students to figure out how they will fit. Can technology substitute for some skills for them?
     o We mostly were looking for ways to make the health care careers more visible and tangible for students, finding internships or mentoring opportunities, something that can be implemented quickly at our institutions that would get students talking about opportunities.
     o For employers, it is important to showcase successful deaf individuals. And finding ways to highlight technology that has changed the workplace, making people more productive than they were a few years ago.
     o Parents came up. Parents have to know and be advised as well. What are the opportunities for your deaf child?
• Accessibility/Technology Subcommittee
  o The technology was confusing and we didn’t know where the information was coming from.
  o We started from scratch and made a lot of changes. We did keep some sections. We wanted to show you the key concepts.
  o We thought the dissemination portion was important. We wanted to set up what is called a clearing house where people can go to get all the information possible.
  o The important concept is the information sharing and access to resources and the partnerships. Students often don’t know how to access the opportunities with schools and hospitals. The technology will show them what is out there and available.
  o The bottom paragraph has the development of video tapes, how to work the equipment, etc. We can develop those videos and pod casts. Those are important.
  o To be more efficient we need to go ahead and provide captioning.
  o We also need consulting services, either communication or technical services available.
  o We need to find the best way to use the technology, to either develop it or look at what is currently there and develop it for best use.
  o Certification of interpreting programs.
  o We talked about testing and evaluation process. We want to be sure equipment for deaf students is effective for them. Either they test it themselves or we have a testing facility for them to come in and test it.
  o Alliance between different companies. We have made some already of course. Cardionics is one. Of key importance is having the training, and setting up the chance to demonstrate some of these pieces of equipment.
  o The interpreting and the communication piece are very important as well. We want more chances to teach and train interpreters and learn strategies for the health care field, providing students with the best way to get interpreting. We want to encourage interpreters to get into the medical field as a specialty as well.

Governmental Policies/Research Subcommittee
  o Ask the governmental experts to contact representatives on a federal and local level to see what we can tap into right away for funding. Identify the two most important short-term solutions in each category that are key to go to the representatives with; what we feel is most important. And we want to know what we can tap into now and get things started in the next 12 months.
  o Accessibility issues - tapping more directly into federal or local money that is already available. As an example we gave a DC program that exists interpreting funds. We could approach this group and say ASL should be included. How can we tap into this
money immediately? We focused on medical service providers and training programs for medical providers.

- Pilot education projects that are short-term that we can request funding for, like academies, including looking at our own institutions and what programs we have that can be expanded for short-term development.
- We looked at doing something for the summers of 2011 or 2012, using the resources we already have at our institutions.
- Speakers Bureau - two focuses for that: consumers, parents and employers. There are people we can identify as experts who can do one-hour presentation to get the information out there.

2. Afternoon Subcommittee Breakout Sessions

Recommendations:

- Long-term recommendations. Maybe it would be more effective to start with the big conceptual issues that haven't been discussed yet:
  - For example, it has come up in our discussion relative to accessibility issues and costs, whether we should advocate a centralized financial government fund that will pay for interpreting and training professionals. Do we want to pursue that or not touch it and leave it to the institutions to monitor their own interpreting costs? That is a big issue.
  - Another example: should we be advocating for specified training programs or centers of excellence, or should we be helping any school become more deaf friendly? That is a big issue we haven't agreed on it.
  - Should we pursue (in terms of the legislative group) identifying deaf and hard of hearing as minorities so we can get the benefits and funding of a minority school?
- We want you to talk about and wrestle with these big issues of direction and obviously there will be some long-term recommendations attached to them.
- Think outside the box, and the long-term recommendations you think are worth pursuing.
- Obviously the long-term recommendations activity will require more research, thinking and information. If you can identify information you need, resources that you need, help that you need, clarify those and that will be helpful.