

Minutes

National Institute on Deafness and Other Communication Disorders Meeting on Biomedical and Behavioral Research Career Opportunities For Deaf Individuals

October 21, 2002

Marriott's Bethesda Residence Inn
Bethesda, MD 20814

The NIDCD Meeting on Biomedical and Behavioral Research Career Opportunities for Deaf Individuals convened on October 21, 2002 at the Marriott's Bethesda Residence Inn at 1:00 P.M. A copy of the meeting Agenda (Appendix 1) and the list of participants/attendees (Appendix 2) are attached to these Minutes. After welcoming comments, the co-chairs asked the meeting participants to introduce themselves and then reminded the group of their two-part charge: 1) Identify obstacles or opportunities for deaf/hard of hearing (HoH) individuals pursuing research careers. 2) Develop recommendations for how NIDCD might address disparities and/or take advantage of opportunities that are identified.

Several panel members provided additional materials and/or made presentations to provide additional information for the panel's consideration. A list of those materials is provided as Appendix 3. The additional materials/perspectives stimulated discussions and helped to motivate the observations and recommendations that the panel generated.

General Comments offered by the Panel:

While progress has been made in recent years since passage of the Americans with Disabilities Act (ADA) to provide access to deaf and HoH students and scientists, most of this access has been in areas of formal instruction such as in the classroom or public lectures. Many deaf and HoH students and scientists report that they find it difficult to gain access to informal areas where information is exchanged and associations between fellow students and colleagues are built. For example, while students can get support for classroom lectures, they find less possibility of access to study groups, lab settings, and other forms of information exchange outside the classroom. Additionally, Universities often do not distinguish between undergraduate and graduate student experience and treat both levels equally, making it difficult for graduate students to obtain support for the varied forms of learning that they encounter. Scientists too often must educate their institutions on how to support them in their efforts to advance in their careers and make special efforts in obtaining adequate support at research conferences and informal forums.

Furthermore, as a result of the ADA, there are more deaf and HoH scientists who are now at the beginning of their careers in laboratories and academic departments. Resources to encourage more deaf and HoH scientists in the biomedical sciences need to address specifically career advancement as well as pre-professional development at the undergraduate and graduate levels.

Deaf and HoH scientists advance through training and careers in different ways. Some use sign language interpreters, some use real-time captioning, and others are more comfortable with other kinds of support. Institutions endeavoring to support the advancement of deaf and HoH scientists should remain flexible about what kinds of accommodation are needed. Control over the selection of support resources should remain in large part at the level of the user - that is, at the level of the deaf and HoH scientist, or scientist-in-training.

Institutions seeking to increase the involvement of deaf and HoH students and scientists in the biomedical sciences need to find ways to educate high school and undergraduate students about equal access to education and information. Young students may be intimidated about approaching their superiors and asking for services, such as an interpreter or real-time captioning. Without experience watching deaf and HoH scientists use such services, young students may find it difficult to imagine themselves as scientists successfully navigating the demanding tracks of professional training and career advancement. Institutions dedicated to expanding the pool of scientists need to find ways to teach deaf and HoH students about the possibility of these resources and realize that these special efforts need to continue during the years of postdoctoral research and career development.

Specific Comments Offered by the Panel Regarding ‘Obstacles And Opportunities’:

Obstacles

One reality is that most deaf/HoH individuals, not just students and developing researchers, have a significant dependence upon communication in a visual mode (lip reading, American Sign Language (ASL), Computer assisted real-time transcription (CART), etc.). This dependence upon visual communication, in addition to all of the other visual information that must be absorbed and processed, constitutes a significant strain and is a potential obstacle.

The currently available infrastructure for educational and scientific resources isn't sufficient for deaf/HoH individuals to have adequate access to the needed information.

Role models are essential in initially stimulating interests in a career direction, and then to help an individual actually pursue and fulfill that aspiration. One common source of role models is parents or other family members. One obstacle to stimulating interests in biomedical and behavioral research careers is the dearth of identifiable role models. Available role models are not only required to inspire young students, but also must be known to the parents of deaf/HoH children so that they can help engender or support their child's interests in a scientific career. A very different type of role model, one that is not commonly available, is the mainstream educator or scientist who has developed ways to successfully communicate and truly reach their deaf/HoH students.

Interpreted education as it currently exists is often inadequate. In most cases for deaf/HoH students, there is a lack of direct communication with professors/teachers. This educational setting requires a third party (interpreters) and this leads to sub-optimal (or delayed) communication. In addition, educational interpreting is generally limited to the formal classroom setting, not the informal educational settings (study groups, poster sessions, Q&A

sessions, break periods, etc.) that are extremely important. There needs to be a process that allows everyone to communicate on the same level. The ideal situation would be where educators deal directly with their students, without interpreters, an outcome which would result from having more deaf/HoH or knowledgeable hearing scientists in professional settings where they can in turn train a younger generation of scientists.

Informal learning, the education that occurs outside of the classroom or lecture hall, is not well served by the currently available interpreting and communication services. Even in primary and secondary school levels there is a wealth of informal education that happens outside of the traditional classroom. Traditional communication services for deaf/HoH students often don't extend into these informal settings. The importance of these informal educational settings increases dramatically as a student moves to graduate, postgraduate, and even early career levels. The nuances of conducting research, writing research grant applications and understanding the special requirements of scientific publication are abilities that are essential for a productive career in science, but are not taught in standard courses. Much of that knowledge is taught in informal research settings where deaf/HoH individuals are often disadvantaged. When breaking into a career in science, a student needs to become immersed in the culture, usually by joining an established research team. The research team, or laboratory, can be viewed as a subculture where the junior investigator gains acceptance, develops their credentials, and establishes/expands their network connection to other research groups.

Opportunities

Technological advances in communication methods, like e-mail and real-time captioning, have helped to address some communication barriers. It is likely that technological advances in the future will help to reduce the communication barriers even further and may more readily extend into some of the informal settings mentioned above.

Research supplements to existing research grants, most notably the NIDCD research supplements for deaf/HoH individuals, have been a vitally important mechanism to get deaf/HoH students into vigorous laboratories where they can receive direct training/research experience. This program is beginning to bear fruit since some of the early recipients are starting to emerge as independent researchers.

Outreach programs to encourage deaf/HOH individuals to become curious about science or to actually pursue scientific careers have yielded positive results, but such efforts need to be expanded. Several examples were mentioned including, the NIDCD research supplements program mentioned above. Related outreach programs include (not an exhaustive list, just some examples):

Leadership Enrichment Adventure Program (LEAP)
(<http://www.agbell.org/news/studleap.cfm>).

The Alexander Graham Bell Association for the Deaf and Hard of Hearing has organized LEAP—an intensive leadership training program designed to help develop skills in individual leadership, teamwork skills, conflict resolution, and problem solving. The program is for sophomore, junior or senior college students with hearing loss who use an

oral approach to communicate—with plenty of opportunities to improve communication skills and share experiences with hearing loss.

Leadership Opportunities for Teens (LOFT)

(<http://www.agbell.org/news/loft.cfm>)

LOFT is a preeminent leadership program for teenagers with hearing losses, held prior to AG Bell's Biennial Convention. This program is intended for high school students, between 15 and 19 years of age, who have a hearing loss and use the auditory approach to communicate. The program consists of a mix of social, leadership, advocacy, team building, creativity, and self-esteem-building activities.

Explore Your Future (EYF).

(<http://ntidweb.rit.edu/eyf/overview.php>)

The National Technical Institute for the Deaf at the Rochester Institute of Technology offers Explore Your Future (EYF). Explore Your Future is a week-long transition education program for deaf and hard-of-hearing high school students entering their senior year in the Fall of 2003. EYF allows students to: 1) Have hands-on experience in a variety of career areas, 2) Make better decisions about their lives after high school through personal awareness, and, 3) Experience life on a college campus.

Gallaudet University has a number of special programs that are held on weekends or during the summer. Past programs have included those focused on technology in hearing research and programs for high school biology teachers of deaf student. A current program is:

Health Careers Opportunity Program (HCOP)

(<http://clast.gallaudet.edu/summer/HCOP.html>)

The HCOP Summer 2003 program includes courses and activities about English and math enrichment and/or test-taking skills, computer skills training, American Sign Language and/or Deaf Culture, psychology, discovery activities, and career awareness and mentoring.

Specific Recommendations Offered by the Panel:

During the panel's discussions, the repeated goals were to encourage individuals to pursue research careers by providing outreach activities and other forms of empowerment. The panel also indicated the importance of promoting the recommendations of this group. Many of the recommendations provided by the panel cut across the goals of encouragement, outreach, empowerment, and promotion. Similarly, several of the recommendations have overlapping or reinforcing themes. An effort has been made to group these related recommendations when appropriate. The recommendations include the following (not listed in priority order).

Develop and make available an inventory of role models and speakers. The inventory should include deaf/HoH scientists and information about their scientific pursuits, photographs, biosketches, training history, contact information. This resource could serve as a forerunner to

other suggestions: camps, conferences, grant writing workshops, etc. The inventory could also include information about topic areas for those willing to serve as speakers. This portion of the inventory might include hearing researchers with appropriate topic areas and/or experience training deaf/HoH students. The inventory could be supplemented with brochures designed to highlight career opportunities for deaf/HoH individuals in science, biotechnology, related fields, etc.

The NIDCD web site only reaches, or is only geared to, students at the graduate level. Younger students need a web site that addresses their issues. If this is not appropriate for the NIDCD web site, the above recommendation is even more important and the NIDCD website might direct deaf/HoH students to that site. In either case, the NIDCD website should have a clear mechanism that allows students to identify NIDCD funded research labs.

Develop an outreach effort to national science teacher groups. Such an effort might include a web site for mainstream science teachers of deaf/HoH students to interact with each other and share practical tips/strategies. A current resource that starts along these lines is the Clearinghouse on Mathematics, Engineering, Technology and Science (COMETS) website, an information dissemination project funded by the National Science Foundation to enhance science, technology, engineering, and mathematics education for deaf and hearing students.

Develop an outreach effort for people who work with deaf/HoH about better ways to communicate in real life work settings. The outreach effort could include lab directors learning sign language, or acquiring skills in communicating by other means, real life examples of what works, methods to quell some of the concerns of the hearing co-worker or supervisor, and a forum for information exchange.

Expand the use of interpreters (and appropriate communication aids) into informal educational settings such as study groups, poster sessions, Q&A sessions, break periods, etc. The need for interpreting/captioning services extends beyond the early educational settings. Professional research conferences need such services extended to their informal components, such as social gatherings, meals, coffee breaks, etc.)

Develop curricula and programs to help deaf/HoH students develop the appropriate background to be competitive when entering college (e.g., chemistry, biology, mathematics, information technology, biotechnology, etc.). The importance of strong English skills needs to be emphasized since English is the common method of communicating science.

Schools for the deaf should invite deaf/HoH scientists to lecture and encourage students to intern in science settings. Lectures and other science oriented activities during the school year would supplement summer science camps (mentioned below). The panel recognizes that these activities would benefit all deaf/HoH students, including those enrolled in mainstream schools, and would encourage sharing of available opportunities when possible.

Develop an opportunity for deaf/HoH professors, scientists, educators, and students to meet and support each other in a direct manner. Such interactions would help deaf/HoH students understand how to overcome daily on-the-job obstacles (mostly communication based). In the

long run, such interactions would help build a critical mass to impact specific areas of education, professional fields, and decision making.

Establish a mechanism and funding source for science internships. Internships have yielded good results, even at the high school level, and a formal and broader program is warranted. When encouraging careers in science the general feeling is the-earlier-the-better.

Devote a concerted effort to equalize the educational ‘playing field’ at the early stages of academic development. One step might be to require that all videos used for educational purposes be captioned. Another step might involve increased efforts to promote science as a career path for deaf/HoH students at the elementary school level and higher. Students and teachers need to be reached by providing appropriate access to the latest science and educational information and by making science more interesting, challenging and inviting for deaf/HoH student. Two ideas for accomplishing these goals are to: 1) develop a web site with information targeted to deaf/HoH students; and, 2) develop science camps (see below). The need to facilitate early access to the best schools, training, and research environments is proposed in recognition that in the higher levels of the scientific community, scientific acumen and accomplishments are the primary criteria used when competing for grants support or faculty promotions.

Develop science camps that have a strong follow up component to reinforce the progress gained while at camp. Science camps already exist for hearing students and related camps, promoting sports and leadership, exist for deaf/HoH children. Such camps represent another opportunity to include deaf/HoH scientists as mentors and role models.

Design methods of encouragement to reinforce accomplishments in scientific arenas. Encouragement could be in the form of prizes for science competitions, projects, or scholastic achievements; prizes might include enrollment at science camps and escalate to include scholarships.

Design and support research conferences with a focus on developing deaf/HoH researchers. Such conferences could take several different approaches. One approach would focus on bringing together undergraduate science students. Some have been convened at the University of Rochester in the past. Another approach might be a ‘self-help’ conference for graduate students to identify and work through issues themselves related to developing scientific careers. Some additional approaches could be to hold a conference that targets deaf/HoH scientists across all levels of training and career development, or to include mainstream teachers and interpreters who might benefit from a conference with this focus.

Conferences should be developed (or better integration of deaf/HoH individuals at existing venues) on how to do research, develop a protocol, design statistical approaches, present a competitive grant application, etc.

Facilitate the incorporation of deaf/HoH individuals (students/postdocs/junior investigators/established PIs) into research lab groups. Research labs represent a scientific subculture where the junior investigator gains acceptance, develops their credentials, and establishes/expands their network connection to other research groups. This point builds upon

the need for science education, science fairs, and science camps delineated earlier, and may benefit from the inventory of role models that has been proposed. Integration into a lab group is an important step in building a ‘critical mass’ of deaf/HoH scientists and mentors.

Set up dialogs (such as at the Association for Research in Otolaryngology and other scientific organizations) with recently trained scientists and/or mentors to develop suggestions for better integrating deaf/HoH students into laboratory settings (esp. informal settings where important interchanges occur).

Directly empower the deaf/HoH student or researcher by placing control of interpreting/support services directly in their hands. Assure more flexibility in the available services – including the types of service, from whom, when and where. This empowerment should also include the ability to select interpreters with special expertise/training, or where a special relationship has developed (a dedicated and limited interpreter pool has worked well for some deaf individuals). The ability of deaf/HoH individuals to take charge of their interpreting/support needs (a form of self-advocacy) is often learned in mentored relationships.

Develop an outreach program for deaf/HoH individuals that is modeled after the successful MARC (Minority Access to Research Careers) program that already exists at NIH. The success of the MARC program could be built upon by using a similarly structured name like, Deaf Access to Research Careers (DARC).

Support research efforts to increase technology based approaches for communication. One idea is to increase the use of CART into wider areas or explore additional functionality. Technological approaches empower the user by reducing dependence upon another individual and are more easily extended to events that fall outside typical ‘school days’ or ‘work days.’

Efforts should be made to build upon the knowledge and/or current capabilities of other organizations. For example:

The Association of Medical Professionals with Hearing Losses (AMPHL) is dedicated to clinical issues and also has a deaf/HoH research focus during one day of its annual November meeting.

The Delmarva Foundation for Medical Care has an interest in people working in deaf/HoH services research and conducts projects for Medicare and Medicaid Services to improve the quality of care for deaf/HoH adults. (Resources for Improving Health Care to Deaf and Hard of Hearing People)

The Association for the Advancement of Science (AAAS) maintains a directory that has been useful for networking and/or identifying potential mentors. AAAS currently has a site for “advancing science/advancing careers” aimed at increasing the science and technology workforce and addressing the needs of young scientists early in their careers.
(<http://recruit.sciencemag.org/>)

The above site contains links for: Job Alerts; Resume/CV Database; Career Fairs; Advice & Perspectives; and Science's Next Wave, the career development resource for scientists. (<http://nextwave.sciencemag.org/>)

The National Science Teachers Association (NSTA) has strong teaching resources that extend into the areas of disability, with some efforts into deaf/HoH students.

The National Center for the Dissemination of Disability Research has a useful website with resource lists and access to databases.

The recommendations of this group should be promoted broadly. Dissemination efforts should particularly include those organizations that have websites and/or hold conventions for the deaf.

The meeting was adjourned at approximately 4:50 P.M.

We certify that, to the best of our knowledge, these minutes are accurate and correct.

_____/s/
Patrick Brookhouser, M.D.
Co-Chair

_____/s/
Carol Padden, Ph.D.
Co-Chair

Agenda

***National Institute on Deafness and Other Communication Disorders
Meeting on Biomedical and Behavioral Research Career Opportunities
For Deaf Individuals***

October 21, 2002

Marriott's Bethesda Residence Inn
7335 Wisconsin Avenue
Bethesda, MD 20814
Montgomery Conference Room

1:00 p.m.	Welcome	Dr. Craig Jordan
1:05 p.m.	Introductions and statement of the committee's charge	Dr. Pat Brookhouser Dr. Carol Padden
1:15 p.m.	Panel Member Presentations (approx. 10 min. per presentation) (consult handouts)	Dr. Pat Brookhouser Dr. Robert Davila Mr. Robert Sidansky Dr. Peter Steyger Dr. Ted Supalla
2:05 p.m.	Identify obstacles for deaf/HoH individuals pursuing research careers	Members
2:35 p.m.	Identify opportunities for deaf/HoH individuals pursuing research careers	Members
3:05 p.m.	BREAK	
3:15 p.m.	Develop recommendations for how NIDCD might address disparities	Members
3:45 p.m.	Develop recommendations for how NIDCD might take advantage of opportunities	Members
4:15 p.m.	Reflections, Discussion, & Summation	Dr. Pat Brookhouser Dr. Carol Padden

Rev. 10/15/02

***NATIONAL INSTITUTE ON DEAFNESS AND OTHER COMMUNICATION
DISORDERS MEETING ON
BIOMEDICAL AND BEHAVIORAL RESEARCH CAREER OPPORTUNITIES
FOR DEAF INDIVIDUALS***

OCTOBER 21, 2002

MEETING PARTICIPANTS

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Executive Secretary

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Appendix 2

MEETING ATTENDEES

Henry Adler
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Derek Braun
NCI

Judith Cooper
NIDCD

Matt Hayat
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Kay Johnson Graham
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Raymond Merritt
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Kristin Piorkowski
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Daniel Sklare
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RESOURCES

(Supplied by meeting participants.)

MATERIALS SUPPLIED FOR THE MEETING

Brookhouser, P.E., Sullivan, P.M., Eccarius, M.A., Schulte, L., Maliszewski, S., and Madrigal, R.: Hearing Research Career Development for Deaf Students. *Laryngoscope*, 104: 1105-1114, 1994.

Feedback from deaf and hard-of-hearing ARO members
Attached as Appendix 4

Assessing Workforce Needs in the Biotechnology Industry
<http://www.cbet.org/> (select "Study Results")

Regional Approaches Seen as Key to Biotech Growth. [Rochester Bus. Jour. 4-5-02]
http://www.rit.edu/~930www/Proj/News/inthenews/2002-06/04_05_02_Biology.pdf

RIT Seeking \$15 Million for Biotech [Rochester Bus. Jour. 3-22-02]
http://www.rit.edu/~930www/Proj/News/inthenews/2002-06/03_22_02_Biotech.pdf

Testimonial for the NIH Focus Group: **Essentials of infrastructure to ensure full access**
Attached as Appendix 5

Delmarva Foundation for Medical Care
<http://www.dfmc.org/>
Resources for Improving Health Care to Deaf and Hard of Hearing People
<http://www.deafhoh-health.org/>

Earth Science Web Site: A New Tool for Deaf Students (and Others)
<http://www.ucar.edu/communications/newsreleases/2002/dlese.html>

National Science Teachers Association
<http://www.nsta.org/search>

National Center for the Dissemination of Disability Research
<http://www.ncddr.org/>

The Postsecondary Education Programs Network (PEPNet) Grants Information page
<http://pepnet.org/grants.asp>

The Association of Medical Professionals with Hearing Losses, AMPHL
<http://www.amphl.org>

MATERIALS SUPPLIED AFTER THE MEETING

2003 National Training Conference (NTC) for Deaf and Hard of Hearing Government Employees

<http://www.dhhig.org/ntc/geninfo.html>

Clearinghouse on Mathematics, Engineering, Technology and Science (COMETS).

This website provides many resources, including informational pages and complete "workshops" on a variety of topics, which can be used individually by teachers, in pre-service teacher education courses as lessons, or as actual workshops for in-service professional development programs to help teachers interested in renewing certification.

<http://www.rit.edu/~comets/pages/welcomepage.html>

AG Bell's Arts and Sciences Awards. Grants are awarded to students with moderate to profound hearing loss to participate in upcoming extracurricular activities in the fields of art or science during after school, summer, or on weekends.

http://www.agbell.org/financialaid/agbell_programs.cfm

Post meeting comments supplied by Ms. Virginia Stern
Attached as Appendix 6

Post meeting comments supplied by Dr. Robert Davila
Attached as Appendix 7

Post meeting comments supplied by Dr. Peter Steyger
Attached as Appendix 8

Post meeting comments supplied by Mr. Robert Sidansky.
Attached as Appendix 9

Feedback from deaf and hard-of-hearing ARO members

(ARO = Association for Research into Otolaryngology);

10 responses: Grad students: 5; Post Docs: 2; Junior Faculty 3

People were asked open ended questions about

- 1) what encouraged them to pursue a biomedical career, or might encourage others with hearing loss to do so.
- 2) what factors discouraged deaf and hard-of-hearing (HoH) people from pursuing a biomedical career, or factors that create problems for those trying to follow a biomedical career.
- 3) What inequalities are out there? What would enable the research environment to be more equitable if there are inequalities out there.
- 4) Potential solutions and methods of increasing awareness.

Common responses :

Mentorship by a HoH or deaf faculty member:

This is considered by several respondees to be the greatest influence that would encourage young scientists to pursue biomedical and behavioral research. There were several reasons raised for this:

- a) Although many people can provide support or understanding; **ONLY** deaf and HoH people can understand the little details [support] which are very important for deaf and HoH folks;
- b) Deaf and HoH post-docs and faculty scientists [can] provide moral support, and role models

Appendix 4

- c) Deaf and HoH students need role models to encourage them to pursue their own science interests; we must promote the NIH's support of individuals with disabilities who are interested in biomedical sciences (see below).
- d) IF deaf/HoH mentors can counsel their charges in deaf/HoH issues, then all the better.

Study habits:

This is a very important component of overcoming hearing loss during education:

- a) use of ALDs, RTC, ASL interps, note-taking assistants vital, students must realize the benefit of such services and overcome the "perceived" stigma of using such technology.
- b) Deaf/HoH students should spend many hours reading the assigned texts in addition to (attempting to) listen to lectures and taking notes. *"Hearing impaired should integrate the textbooks into the lectures. Be allowed to read along. Have a note-taker provided so when he/she is paying attention in class, he/she need not take eyes away from lecturer. Support is key, with an encouraging counselor and understanding teachers, and use of assistive listening devices."*
- c) *"Technology is wonderful, but nothing beats the old buddy system!"*
- d) in each case, appropriate study habits must be developed for the unique needs of each deaf/HoH student.... *"deafness isn't the same in each person"*

Disability Services Departments:

Some Universities were able to provide excellent accessibility, while others were not

There were consistent requests

- a) Greater understanding of HOW ALDs/RTC/CART/remote CART/ASL interps etc work (and lack of understanding how they work, or correct implementation; often remote CART substituted for CART) by staff members in Disability Services departments.
- b) Better provision and more consistent application of ALDs/RTC/ASL interps etc by Disability Services departments in Higher Education, and uniform provision across the nation.

Inequalities:

- b) Lack of note-taking, CART or assistance in lectures and classes for undergraduates and graduates.
- c) Lack of teacher awareness (turning around to face slide/chalkboard during seminar).
- d) Lack of ALD/RTC/CART/ASL provision during conferences, when time and energy are at a premium. Conferences induce tiredness more rapidly, eyestrain, auditory/visual overload of information etc in deaf/HoH attendees.
- e) Lack of ALD/RTC/CART/ASL provision in some departments that have deaf/HoH staff/student members for seminars classes etc.
- f) Some felt that each individual deaf/HoH person should not have to manage their own ALDs arrangements individually (debatable).
- g) Medicine: stethoscopes and opaque surgical masks pose obvious difficulties for listening or lip-reading respectively.
- h) Becoming less frequent in society, but patronizing attitudes and lack of awareness still occur in academic and workplace environments, particularly during recruitments.
- i) Peer pressure is very evident on young scientists, and especially graduate students, this can be crippling when young disabled scientists lack confidence in their abilities, thus strong, positive mentors are required.

Potential Solutions:

- a) Mentor-Student matching service, this is vital to provide mentors with appropriately matched students (or vice-versa)
- b) Enhanced CART/RTC/ASL provision at conferences
- c) Research internships between Deaf/HoH researchers and deaf/HoH students (high school/undergrad/graduate)

Appendix 4

- d) Greater understanding of HOW ALDs/RTC/ASL interps/CART/remote CART etc work (and the technology classroom schedules needed for them to work effectively) by staff members in Disability Services departments
- e) Better provision and more consistent application of ALDs/RTC/ASL interps/CART/Remote CART etc by Disability Services departments in Higher Education, and uniform provision across the nation.
- f) Medicine: amplified stethoscopes and transparent surgical masks (?).
- g) Continued (and enhance?) promotion of the **Research supplements for individuals with disabilities** program (see below for details), this is an essential and valuable program that promotes the infusion of people with disabilities into the faculty and thereby facilitating greater awareness and acceptance of those with disabilities.

Hearing Research as a valuable scientific training ground for young Deaf/HoH scientists

Perhaps the best arena for such training for several reasons:

- a) More (but NOT most) researchers in this field are aware of issues facing deaf/HoH scientists
- b) This research field is more accommodating, not just in willingness to provide assistive services, but also in personal interactions because researchers are more knowledgeable about hearing loss. In other biomedical fields, people don't necessarily even know what assistive listening devices or RTC are.
- c) Deaf and HoH post-docs and junior faculty are willing to recruit (and have been recruiting) deaf/HOH students for summer internships, which encourages students to pursue biomedical fields.
- d) The research environment is potentially one of the most accessible, and aware employment arenas for disabled people. One respondee (and another concurs) writes: "*I know (because I was told by senior faculty) that my presence in a research lab enabled them to learn at first hand what the impact of hearing loss meant to a person and their interaction with the able-bodied world, and that this was an education for them.*".
- e) One's own deafness is a great motivating factor that encourages researchers to keep asking questions of why and how hearing loss happens

Research supplements for individuals with disabilities

This program was praised by three individuals as being the major factor in promoting their careers at crucial times. This program is near maturity now that these same deaf/HoH individuals have or are about to apply for R01 grants that could use these supplements.

One resposdee wrote: "[My mentor and] I applied to the NIDCD for postdoctoral support for individuals with disabilities and received this support. ... The NIH is in large measure responsible for my staying with biomedical research ... I needed the NIH support ... so that I could learn the literature of a new field and write my first grant."

Another wrote: "The supplement program allowed me to move into a vigorous research lab that provided me with the skills necessary to set-up my own independent lab and successfully write my own R01. This would not have been possible without the Supplement program."

A third wrote: "[my mentor] had written "100s" of letters of references for [faculty positions] to mainly [academic] departments in the US. It was dawning on [my mentors] and me that [academic] faculty even in the US were still blinkered in terms of what deaf people can do.

This program has in different circumstances and cases has provided an infusion of young faculty members and is continuing to produce talented graduate students and post-docs who will (in time) be eligible for faculty positions. This program is strongly supported in this context.

Note: CART (Computer assisted realtime transcription; east coast) = RTC (real-time captioning; west coast)

Testimonial for the NIH Focus Group
Sept 21, 2002

Essentials of infrastructure to ensure full access

Ted Supalla, Ph.D.
University of Rochester

We may agree in principle that Deaf scholars and researchers need to have full access to public and private University facilities (i.e., a more visual curriculum and facilities designed for visually-oriented learning and teaching) as well as the opportunity to obtain support services from society (i.e., quality interpreter services) to facilitate access. However, the main obstacle in achieving full access is the lack of infrastructure in both our society and Deaf community to support our ventures as scholars and scientists.

Because of limited resources and social traditions toward minority groups, our society has not invested in building an efficient infrastructure for supporting and promoting learning and empowerment for Deaf scholars and scientists. This infrastructure problem has not yet been addressed in the societal dialogue on strategies for promoting inclusion of deaf and hard-of-hearing citizens. For instance, the most popular strategy chosen for breaking barriers in educational settings is to place an interpreter in the situation, to facilitate interaction between a deaf person and a mentor who may not know sign language. The implementation of “Interpreted Education” in the last 30 to 40 years has had an enormous impact on educational opportunities and subsequent job placements for deaf and hard-of-hearing consumers. Yet this system has certain inherent problems. For example, although not on purpose but by the nature of the dynamics of the interpreting process, the consumer in this strategy takes on a passive role, as a ‘client’ whose needs are taken care of by service providers. As a consequence, there is little accountability or quality assurance in the system. Deaf consumers often feel so grateful for interpreting services that they do not consider, or are not asked, whether their interpreters are excellent or can be fully understood. Interpreters are often not screened adequately for their production or comprehension of ASL. There is thus not always a reliable and dependable infrastructure for supporting our efforts to become independent thinkers and be part of the academic/scientific world.

In my opinion, this is the root of many problems and issues we raised and debated at the Deaf Academics Workshop, March 8-10, 2002, at the University of Texas at Austin (see attached copy on the rationale of the workshop and the topics covered there). I believe that if this infrastructure problem remains unresolved, we will continue being unable to achieve our potential (either as individuals or as a group) to make contributions to better understanding of Deaf-related topics and issues, and to participate in other academic activities and scientific ventures in society (see attached copy of the Amsterdam Manifesto in regard to the International Conference on Theoretical Issues on Sign Language Research in 2000).

To facilitate discussion in the NIH Focus Group of how to develop a consumer-friendly infrastructure for ensuring full access into the academic and scientific world for the deaf or hard-of-hearing individuals, I am prepared to share my perspectives on ways to improve

Appendix 5

connections to the academic/scientific world. In particular, I will discuss personal experiences in three areas of interacting with people: 1) interacting with colleagues and students while undertaking research apprenticeships during graduate school, performing scholarly mentorships with deaf and hearing students, and participating in a variety of peer-review and democratic processes in the academic and scientific communities; 2) working with interpreters for facilitating my diverse roles as lecturer, participant, and consumer in classroom settings, conferences and personal interactions; and 3) collaborating in a variety of research projects, community service and task forces with colleagues, policy makers, and civic leaders. The goal is to give some idea of what the academic life of a Deaf scholar looks like and what kind of support system would be ideal for maximizing access to resources and facilities for scholarship and research.

Attachments:

- Austin Workshop 2002.pdf
- Austin Workshop Program.pdf
- Amsterdam Manifesto.pdf

Post meeting comments supplied by Ms. Virginia Stern.

"DARC" program (the acronym excludes other disabilities, of course), I believe NIDCD has to start by establishing summer or term-time internships for undergraduates on the NIH campus or elsewhere, so the students will have some exposure to real research in these fields and decide whether it interests them enough to persist. I know from the experience my AAAS colleagues have with MARC students that the MARC mentors on campus are encouraging them all the time to stick to certain majors so they will be MARC-eligible, and then eligible for the pre-doc programs that follow. Very few students who are deaf or have any kind of disability are receiving this kind focussed mentoring.

The other important point, which both Dr. Brookhouser and I made at the meeting, is that the students who are academically talented and might want to persist to the doctorate are distributed throughout our whole higher education system. The recruitment to identify them has to be national. It is unlikely that you would find more than one eligible student in any one institution over a 2-3 year period. However, if you did a national search you could find 3 -5 students one year and 3-5 more the next year. (In the 6-year AAAS ENTRY POINT! program with NASA, we have placed 124 high-achieving students with disabilities in internships and they come from seventy different higher education institutions.)

Of course if you gave institutional grants to Gallaudet, NTID, and Northridge you would have a pool to start with. But you would miss the talent that is distributed in other institutions and students who are possibly enrolled in higher quality courses in biology and other sciences. These internships (or student training, if NIH prefers that terminology) need to be support for individuals who have demonstrated achievement in a whole range of schools.

Pat is right that parent expectations are more important than communication choices or other variables. But it is the mentor that a student meets working in a lab that changes that students expectations and the student then educates his/her own parents. Even if the parents have never met a role model in science, they rarely discourage a student once a student has a mentor. (This is true of the minority students as well.)

I do not think this is a critical mass issue at all. Pursuing a doctorate can be lonely even for students with no disability. There may be economies of scale in providing support services at entry-level classes, but as soon as a deaf student gets into a specialized field in his/her science, there will not be another classmate to share the interpreter or CART service. Students who need support services at lectures, meetings, social events simply have to learn the best way to ask (demand) them. This is a perfect world, but the students can get a lot more if they explain why they need it.

There is more to say, but perhaps this is enough now. If you go in the direction of DARC or a similar program, our office at AAAS would be pleased to partner with NIDCD on a national plan to recruit students.

Post meeting comments supplied by Dr. Robert Davila.

A cursory survey of some of our alumni (from NTID/RIT) resulted in a listing of over 75 graduates who majored in biotech studies/fields. We have not updated the information to determine how many of them are actually employed in biotech fields, but it is safe to assume that there are a number who are. This small population might be worthy of a study to determine the issues of content knowledge, work skills, work procedures and social interactions that pose issues of access on the job. I believe such a study would produce a more detailed and relevant listing of issues and obstacles that would guide career counselors and program planners in biotech areas.

I also shared information with the group about Upstate New York's efforts to develop biotech into a signature employment niche. The New York State Legislature has made large grants to the consortium consisting of the University of Rochester, RIT and Alfred to develop its biotech fields of study. In fact, this is timely and beneficial for NTID because many of our NTID/RIT graduates find employment in Upstate New York and remain permanently following graduation.

Students in biotech study fields generally arrive at college with a strong interest and aptitude in science fields. College is hardly the place to arouse that interest unless the student arrives with a strong base of high school science courses. In this case, the availability of career options involving science may attract such undeclared students.

I also believe that lab work also gives deaf students opportunities to work independently and individually for periods of time and this may be a factor as well. RIT is strong in technology, engineering and science and that is why we are more likely to get students who have the required preparation. Again, Upstate New York is one of the nation's hubs for the biotech industry and the availability of jobs tends to influence study and career choices.

Post meeting comments supplied by Dr. Peter Steyger.

1) Hard-of-hearing students and scientists have very little sense-of-community or networking opportunities and would welcome the opportunity to mentor teen/college students in their own institutions or at leadership/science camps. Since the focus group met, I have been made aware of the following activities which we use as a model to facilitate our own structures for those who are thinking of or are already in the science career track:

i. Leadership Enrichment Adventure Program

(<http://www.agbell.org/news/studleap.cfm>). The Alexander Graham Bell Association for the Deaf and Hard of Hearing invites you to attend LEAP—an intensive leadership training program designed to help you develop skills in individual leadership, teamwork skills, conflict resolution, and problem solving. Best of all, you'll be there with 20 other outstanding college students—with plenty of opportunities to improve your communication skills and share your experiences with hearing loss. It is for sophomore, junior or senior college students with hearing loss who use an oral approach to communicate. It takes place at the National 4-H Center, Chevy Chase, MD—minutes from Washington, DC, during the summer. Stay tuned to the AG Bell website (www.agbell.org) for the dates of the next session. Cost: \$375 tuition, plus the cost of travel to and from the program site. The cost of tuition includes 4 nights lodging, all meals, as well as special event entrance fees, transportation to/from LEAP events, t-shirt and all materials.

ii. Leadership Opportunities for Teens (LOFT;

<http://www.agbell.org/news/loft.cfm>) is a preeminent leadership program for teenagers with hearing losses, held prior to AG Bell's Biennial Convention. Next scheduled LOFT will be Summer 2004 in Los Angeles, California. This program is intended for high school students, between 15 and 19 years of age, who have a hearing loss and use the auditory approach to communicate. The program consists of a mix of social, leadership, advocacy, team building, creativity, and self-esteem-building activities. Thus, the conference will be a great learning experience...plus a lot of fun!

iii. 2003 National Training Conference (NTC) for Deaf and Hard of Hearing Government Employees, which will be held on March 17-19, 2003 at the Natcher Conference Center, National Institutes of Health campus in Bethesda, Maryland (see appendix 1).

iv. Dr. Sam Trychin will come to Oregon this December to lead a 2-day Teen Event up in the hills, not too far from Salem. Dr. Sam was formerly Professor of Psychology at Gallaudet University, and is currently at Pennsylvania State University. He has been leading workshops for Hard of Hearing people of all ages throughout the US for nearly 20 years. Dr. Sam is famous for using humor, drama, video and the unique wisdom he has accumulated from both being Hard of Hearing himself, and listening to other Hard of Hearing people, their families, and friends. His work revolves around the theme “living well with hearing loss”—and thousands of Hard of Hearing people attest to the fact that what he does, indeed, works! (see appendix 2).

v. What kind of leadership programs do the National Association of the Deaf (or state chapters), American Deaf Children's Association etc. have?

vi. These avenues all represent avenues which we can exploit to further our mission.

2) It is extremely important to remember that students who are oral, but have a hearing loss comprise the greater proportion of those who have hearing loss. Many are mainstreamed and yet face considerable difficulty in acquiring the necessary knowledge and acceptance in the hearing world. The same is true also for those from the signing community, but all too-often, the hard-to-reach oral person with hearing loss is overlooked. Strenuous efforts must be made to reach this larger population of students to encourage their participation in the scientific research enterprise.

3) If the goal of the focus group is to make science more accessible to high school and college students, I strongly urge that SHHH (Self-Help for Hard-of Hearing People), Alexander Graham Bell representatives, National Association of the Deaf and other interested groups should be contacted to disseminate our findings, and to incorporate our projects/services and websites for students etc. I met with SHHH and AGBELL representatives following our meeting, and SHHH would like to implement a virtual (cyberspace) mechanism of mentoring young HoH people with appropriate mentors who would ser as role models. AGBell already have similar activities (see above). A webpage listing potential mentors, and most if not all scientific persons who are deaf or hard of hearing would be a valuable low-cost methods of providing information to all current and future deaf and hard-of-hearing scientists and other professionals.

4) If an allied goal is to foster those who have already committed to scientific careers and serve as mentors for the next generation, then a different set of reach-out activities are potentially required to retain such students and scientists and foster their careers. This significant point was lost in the overwhelming discussion on reaching out to high school and college students. Those that have chosen a science career have significant hurdles in their way, including lack of accessibility to conference proceedings, lack of professional network where their work and progress can be validated, and the lack of supportive mentors who will promote their acquisition of the necessary scientific and political skills to forge significant scientific careers. A mentorship, leadership or networking conference for these individuals would be extremely valuable. In addition the incorporation of these individuals in professional society meetings, organizations and speakers/authors in symposia and journals would enhance their status, career tracks and most importantly their self-esteem.

I believe 3: did not emphasize strongly enough one item in the follow-up that is crucial NOW and will become absolutely necessary later as the program to increase numbers of deaf and hard-of -hearing (HoH) researchers proceeds. It is absolutely essential that scientific conferences are made fully accessible to deaf and HoH researchers, because conferences are an essential continuing education (or training) environment for all researchers.

Oral presentations provide the greatest difficulty to deaf and HoH researchers, who will always be at a disadvantage in acquiring new knowledge in an oral environment. Accessibility is achieved through three main methods: real-time captioning, assistive listening devices (ALDs) and sing language interpreters.

The major benefit of real-time captioning is the provision of spoken dialog from the speaker(s) to deaf and HoH researchers, who will not hear or register every word spoken, and will miss words

that are new to their vocabulary. Thus, real-time captioning is a major and essential facet of providing accessibility to science for deaf and HoH researchers, because new topics always entail new words, and seeing those new words written is a major asset for continuing education. In addition real-time captioning is now provided in both high school and college environments for educating students, who will depend on this technology if they are to consider biomedical research disciplines for their careers. Furthermore, real-time captions provide accessibility for the increasing number of older researchers who are increasingly prone to age-related/acquired hearing loss and are not familiar with sign language or ALDs.

The provision of real-time captioning does not negate the usefulness and necessity of American Sign Language (ASL) or cued speech interpreters, or of ALDs, that may also be provided. Interpreters are not always needed if real-time captioning is provided, but there are many situations where ASL interpreters are vital, particularly for the spontaneous interaction between the ASL researcher in asking scientific questions at the end of individual oral presentations, post-session discussions, and during the poster presentations by the researcher who communicates using ASL. These are all normal, but essential activities that hearing people take for granted, and hard-of-hearing, and oral, researchers can cope with in one-to-one situations.

ALDs will always remain an essential tool in providing accessibility at the conferences. It is comparatively cheap and, once set-up correctly, functions for the duration of the conference with little maintenance. Even if real-time captioning is available for every session, ALDs will still be required, because not every deaf or HoH person uses the captions, and the enhanced auditory signal allows for listeners to view the slides as well as the captions. Furthermore, ALDs provide auditory redundancy which is essential for a complete comprehension of the presentation, as eyes often get tired from lip-reading and reading captions.

One example where accessibility has been partially, but successfully, implemented is the Association for Research in Otolaryngology (ARO) MidWinter Research Meeting, the premier conference on basic research in otolaryngology. This conference has had experience and success in providing accessibility with limited funds for several years now, and, if made fully accessible, can provide the template (and experience) for enhancing accessibility for deaf and HoH researchers at other scientific conferences.

The ARO conference is supported by a conference grant from the NIDCD. This conference grant includes funds for real time captioning, allowing partial accessibility of this conference to deaf and HoH researchers. Real-time captioning, along with ASL interpreters and ALDs, have had a dramatic effect in providing enhanced accessibility of oral presentations to deaf and HoH researchers, and for interaction between researchers who depend on ASL to communicate with readers of their poster presentations, and after-session discussions. For the past several years, I have, in conjunction with Judy Dubno (representing ARO) and with assistance from Lina Reiss (Johns Hopkins University, MD), helped to prioritize which oral sessions at the ARO MidWinter Meeting are captioned, to ensure that the ALDs are working properly, and to provide ASL interpreters as required. This improved accessibility for deaf and HoH MidWinter Meeting attendees has been very successful.

Post meeting comments supplied by Mr. Robert Sidansky.

After reading the minutes, I thought of some ideas of how we can promote young deaf and hard of hearing students to enter the science fields. I don't know if it is proper to add this to the minutes, but I feel that it is important for me to share my thoughts with you. If you wish me to give more information or any clarification about this topic, please let me know.

First of all, thank you very much for giving me the opportunity to attend this meeting with you. It was nice to see a group of people who care about our young deaf and hard of hearing people with their dreams of pursuing future careers in science.

Here's my idea:

Develop a science program in a postsecondary program similar to the model of the National Leadership Training Program (NLTP) at California State University, Northridge, which was held back in the 1960's to the early 1990's. The NLTP program was to promote leadership among deaf and hard of hearing people. It increased the employment of administrating and supervising positions in the educational and rehabilitation settings among deaf and hard of hearing individuals all over the nation. It was successful that we were able to reach the potential deaf and hard of hearing leaders to enroll this program along with the critical mass of deaf and hard of hearing individuals who enjoyed similar interests and goals. They developed their own personal networks.

As the result of the program, the graduates of the NLTP were able to find jobs in the area of administration and supervision in educational and rehabilitation settings. In return, the NLTP met with several young deaf and hard of hearing students in their leadership positions in their schools and shared their positive experiences about the program at CSUN. They helped with recruiting students for CSUN. As a result, it had a successful domino effect all over the nation. The publicity was positive among the leaders and, in return, they were able to encourage the young people to be in leaders in the deaf community.

I believe strongly that deaf and hard of hearing people within the science community should develop a similar program with a good reputation such as the NLTP to encourage young deaf and hard of hearing students to enroll in a science program at colleges or universities. It also gives the deaf and hard of hearing scientists the opportunity to be mentors and role models for the younger students and encourages the young scientists to develop their own personal and professional network when they graduate.