FOUNDATION FOR SCIENCE AND DISABILITY (FSD)

Annual Meeting

10:00 AM -11:00 PM, Friday, February 14, 2014

Resource Room for AAAS Annual Meeting Participants with Disabilities Hyatt Regency Chicago, Skyway 261 Chicago, IL

Attendees

Erica Penn, Angela Foreman, Yoshiko Miwa, Kiyomi Deards, Betty Ingram, Richard Mankin

Call to Order/Introductions-Erica Penn

Erica introduced herself as the newly reelected President. She handed out copies of the 2014 FSD meeting agenda, the 2014 FSD newsletter, and the minutes of the 2013 FSD annual meeting. She discussed her work in the biotechnology industry in Baltimore. Angela Foreman discussed her work in the biotechnology industry in San Francisco. Yoshiko Miwa discussed her work as a writer in Tokyo, and presented the foundation with a copy of her recent book about persons with disabilities in Japan. Yoshiko also presented a handout she had prepared about the recent political and institutional changes affecting persons with disabilities in Japan (see Facebook post at https://www.facebook.com/groups/360413492800/). Kiyomi Deards introduced herself as a new attendee and discussed her work as an Assistant Professor in the University Libraries, University of Nebraska, Lincoln. Nebraska. Richard Mankin described some of his recent research on developing a trap for Asian citrus psyllid pests in Florida that uses vibration signals to attract mate-seeking males. He also discussed recent activities interns of interns with disabilities in his laboratory last summer.

Minutes -February 15, 2013, Boston, MA

The 2013 annual meeting minutes, posted at http://STEMD.org, were discussed and approved as written.

Student Science Grant Committee report 2014. The Student Science Grant Committee met by email (members: Angela foreman, Erica Penn, Laureen Summers, and Chair, Richard Mankin). We reviewed five applications that met the grant criteria and selected Amy Elizabeth Nichols, a PhD student in biology at Virginia Tech University, to receive a \$1000 grant in support of Research on "Impact of evolutionary history on litter decomposition."

Treasurer report, Angela Foreman

Angela discussed the Treasurer report, which is presented in the 2014 Annual meeting newsletter at STEMD.org. The report was approved unanimously. Angela also noted that she had submitted the 2013 IRS form and had renewed the Foundation's Washington DC nonprofit status.

New business

Laureen Summers was unable to attend the meeting but she sent us some comments:

Hi Everybody:

I am sorry that a personal matter is keeping me from attending the meeting. I hope it goes well and look forward to a report on this year's Foundation meeting.

There are some items we discussed last year that you may want to bring up again. For example, stories on the experiences and accomplishments of scientists like yourself could be featured in one of AAAS's news websites (Angela was already featured). People really enjoy the stories of successful individuals and this is a good way to encourage students with disabilities to pursue science.

The other idea from last year was to network with other organizations to encourage disability diversity – outside of AAAS. Has anything been done to build on this? Maybe you can make a plan to reach out to a few (keep it small and manageable) science organizations that have not significantly addressed issues of disability and access.

The topic of networking with other organizations also came up at a meeting of the Committee on Opportunities in Science (COOS) of the American Association for the Advancement of Science, February 12-13, 2014. Several members of FSD (Erica Penn, Imke Durre, and Richard Mankin) also are members or advisors in COOS. On February 13 we participated in a breakout session with other COOS participants, Ted Conway, Bob Megginson, and Brad Duerstock. Some of the topics that came up about Science, Technology, and Disability concerns of the COOS committee are of concern to FSD as well.

Three Main issues that were identified were identified in the breakout session:

- 1. Entry Point! funding declines Laureen Summers mentioned this issue over phone conference on Wednesday, February 12, 2014 during the COOS meeting. Suggestion from working group was that Entry Point! needs to be re-evaluated with the goal of increasing the resources available to fund interns. For example, it may be necessary to increase focus on creating new partnerships with alternate agencies (gov't, academia) and the private sector.
- 2. Imke mentioned the need for technical experts made available to AAAS to ensure that technology is available to end users are acceptable. (Small advisory group of Persons With Disabilities(PWD) various disabilities included).
- Example electronic scientific publications should be made accessible to the visually-impaired (the use of MathML for equations instead of graphics for example).
- 3. Need to establish a national venue or society for scientists & engineers with disabilities to become a resource for individuals. There is a need for Focus on:
- a. Entry-level information & support
- b. Career development for mid-level career professionals
- c. Mentoring for both aspects (entry-level & mid-level), leading to professional advancement.
- d. Increased use of social media (Facebook, Skype, etc.) for virtual (online) meetings

Action items suggested for the process of organizing a national venue/society:

- 1. Establish Mission statement & Committee for the new venue/society:
- a. Develop query/questionnaire to obtain input from scientists/engineers with disabilities target the Directory of Scientists & Engineers with Disabilities (from AAAS) and Entry Point! Alumni.
- b. Research and obtain a general idea of the structure of similar organizations to use as model template.
- 2. Establish Beta testers:
 - a. PWD testing technology as it evolves
 - b. Implement universal design for access
 - c. Involve different technologies for different disabilities
 - d. Subgroups of a specific category can become testers
 - e. Develop questionnaire for Beta testers' input.
- 3. Other miscellaneous action items that came up in the breakout session:
- a. First steps charge dues? Website? How to find target individuals? Must establish basic concepts first.
- b. Establish website/forum tie-in to well-known website? How to market? Disseminate to disability communities; schools?
- c. FSD website could be expanded for example to include not only grant applications, but also include narratives, resource info.
 - d. Front page link (direct) ASME (example)
- e. Compliance Experts (committee), Membership (committee), deals with issues of disabilities; liaison committee.
- f. Proposal to NSF (proposed by Ted Conway to help fund the beta testing and resource development process):
- o Needs structure, mission, query & societal impacts included in proposal body.
- o May have to be submitted through AAAS (to receive funding)

Laureen Summers attended the AAAS Meeting on *Advancing Disability Rights through Science* and presented the COOS Committee with this report that also bears on the above discussion:

"Advancing Disability Rights through Science"

Report on the January 27, 2014 meeting of the AAAS Science and Human Rights Coalition.

Location: AAAS – Auditorium

Number of Attendees – 100 including these speakers:

Vincent Cerf

Marco Midon

Robert Dinerstein - Disability Rights Law Clinic - AU

Anju Khubchandani – Disability Issues in Psychology – APA

James Thurston (Suzanne's brother) - International Accessibility Policy - Microsoft

Michael Gamel-McCormick - Senator Harkin's Disability Policy Director

Davis Morrissey - US International Council on Disabilities

Charlotte McClain-Nhlapo - Disability and Inclusive Development, USAID

The focus of this meeting was on disability. It was recommended by the Science and Human Rights Coalition's Steering Committee and arose in part from the interest of some Coalition member organizations in supporting the UN Treaty on the Convention of the Rights of People with Disabilities (CRPD. Disability was also seen as an important human rights issue with high relevance to the science and engineering community, especially the Coalition's work on the 'right to science' (Article 15). (The current Steering Committee members include representatives from the American Psychological Association, American Sociological Association, American Physical Society, American Statistical Association, and the National Center for Science and Civic Engagement, as well as two representatives of human rights organizations.)

There was ample discussion on the ratification of the Treaty. The U.S. Congress is short of six votes to ratify it. Oppositions come from three misconceptions:

- 1. Parental rights (i.e. desire to homeschool) will be limited because of the clause regarding that education be provided in the best interest of the child. The fear is that this will be decided by the government and not by the family.
- 2. Statements in the treaty regarding sexual and reproductive health and interpreted, by some, as granting the right to abortion.
- 3. Risk of losing sovereignty that the UN will take over supervision of domestic law.

The benefits of ratifying the treaty:

- People with disabilities would be much more a part of an international community. They would gain more respect, equal opportunity and reasonable accommodations worldwide.
- Inclusion would be seen as a human right.
- Millions of people with disabilities travel internationally for work and pleasure, and accessibility would improve.
- People with disabilities in the US have skillsets that can be shared.

• Businesses, especially those invested in technology would benefit, because more countries would adopt accessible standards on technology and need US resources.

Science and Technology can be an equalizer for any underserved population and has the power to be transformative. We need to build a wider net of partnerships to encourage disability as part of diversity – to be mentioned in policies and recommendations for program implementation. The USAID policies now mention disability.

Some "nuggets" from speakers:

- 15-18% of population is disabled. 800 million adults; 200 million children.
- Pervasive stigma and segregation continue.
- Reporting on disability often underestimates the numbers and gives a low priority to needs (technology; accessibility; etc.)
- There are 5 billion cell phones being used most are in Africa.
- Vietnam advocates for inclusive education.
- There is mobile banking in Kenya.
- Peru has granted voting right to people with intellectual disabilities.

Interesting remarks from Marco:

- Smart phones worked for people who are blind until Apple developed the touch screen display new technology is not designed for the blind.
- Texting = Marco can only do four words a minute.
- Has to wait for auditory signals.
- ADA does not cover the internet so there are no laws governing access.
- Section 508 states that government should not procure non-accessible technology and should not have allowed the iPhone, but contractors should develop alternatives.
- Technology can take away accessibility.
- There should be a choice of interfaces (on tablets, phones).
- There is a question of how to balance technology benefits, i.e. tablets work well for people with autism, but not necessarily for everyone.
- Disability is an interaction between the person and the environment.
- We continue to design research in ways not helpful to people with disabilities. They should be equal partners.

Vince Cerf: We need to use cultural, financial, and legal means to make assistive technology available to everybody.

Based on the discussion items above, the FSD meeting participants developed an action plan:

The first step would be to form a committee of volunteers to do beta testing.

Yoshiko, Erica, and Angela volunteered to be on this committee.

There was discussion about the costs of the new technology. Frequently the technology is not accessible to persons with disabilities. There was a suggestion that we search for magazines and web sites and technology shows that advertise and describe new technology for persons with disability.

In addition, it was determined that FSD should consider greater focus on mentoring opportunities. For example, we could bring a local undergraduate student to the next AAAS meeting in San Jose relatively inexpensively because Angela lives near there. Especially because San Jose is a hotbed of technological activity. FSD could ask AAAS to give the student a 1 day pass to the annual meeting.

Possible additional support of the Entry point program-was discussed.

Finally, networking was brought up again as a need for future development.

The meeting ended at 11:00.

Submitted by Richard Mankin, 2/15/14