



President's Committee for People with Intellectual Disabilities (PCPID)

~ Minutes ~

November 19-20, 2008 Quarterly Meeting

**Participants**

**Ex officio Members and Representatives**

The Honorable John R. Vaughn  
*Chair of the Board*  
*National Council on Disability*

RoseAnn Ashby  
*Representing the Honorable Margaret Spellings, Secretary, U.S. Department of Education*

Richard Balkus  
*Representing the Honorable Michael J. Astrue, Commissioner, Social Security Administration*

Jewel Bazilio-Bellgarde  
*Representing the Honorable David Eisner, Chief Executive Officer, Corporation for National and Community Services*

Margaret Giannini  
*Representing the Honorable Michael O. Leavitt, Secretary, U.S. Department of Health and Human Services*

Caffin Gordon  
*Representing the Honorable Mary E. Peters, Secretary, U.S. Department of Transportation*

Mark Gross  
*Representing the Honorable Michael Mukasey, Attorney General, U.S. Department of Justice*

Stephen B. Hollingshead  
*Representing the Office of the Secretary of Housing and Urban Development*

Pat Leahy  
*Representing the Honorable Carlos M. Gutierrez, Secretary of Commerce*

Mary Kay Mauren  
*Representing the Honorable Naomi C. Earp, Chair, Equal Employment Opportunity Commission*

Sue Picerno  
*Representing the Honorable Elaine L. Chao, Secretary, U.S. Department of Labor*

**Citizen Members:**

Berthy De La Rosa-Aponte  
Sambhu N. Banik, Ph.D.  
Riccardo Barraza, Jr.  
Jewel Bazilio-Bellegarde  
Stephanie Preshong Brown, via audio conference  
Ollie D. Cantos, VII  
Eric Cole  
Sharman Word Dennis  
Carmela Vargas Gonzales  
Harris Hollin  
Casey Patrick O'Halloran, via audio conference  
Stephanie Preshong Brown  
Steve Rhatigan  
Mary Margaret Sharp-Pucci  
Linda Hampton Starnes  
Stephen H. Suroviec  
Dallas (Rob) Sweezy  
William (Will) Tienken  
Eric Todd Treat  
Mary Ellen Zeppuhar, via audio conference  
Charles Weis, represented by Sharon Bui Green

**Guest Speakers/Presenters**

David Michael Mank, Ph.D.  
Director, Indiana Institute on Disability and Community  
Professor, School of Education  
Indiana University  
Bloomington, Indiana

Robert G. Goldstraw  
Project Manager  
and  
Diana Zeitner  
Communications Coordinator  
DisabilityInfo.gov  
U.S. Department of Labor  
Office of Disability Employment Policy (ODEP)  
Washington, DC

**Special Guests**

The Honorable Daniel Schneider  
Acting Assistant Secretary  
Administration for Children and Families  
U.S. Department of Health and Human Services

Allan I. Bergman  
Anixter Center  
Chicago, Illinois

Dr. Francisco M. Vasquez  
The Museum of Disability History  
Williamsville, New York

**Constituency Group Representatives and Other Guests:**

Annie Acosta  
Carmen Cromartie  
Christey Tucker  
Julia Ward

**Staff:**

Sally Atwater, Executive Director	Kodie Ruzicka
MJ Karimi	Sheila Whittaker
Laverdia T. Roach	

~ **SUMMARY OF PROCEEDINGS** ~  
(Meeting Agenda at End of Summary)

**Greetings, Call to Order, and Introduction of Staff  
Sally Atwater, Executive Director and Federal Official**

The November 19-20, 2008 meeting of the President's Committee for People with Intellectual Disabilities (PCPID) was called to order by Sally Atwater, Designated Federal Official Representative and PCPID Executive Director, who welcomed meeting participants. Ms. Atwater stated that it was her privilege to work on the New Freedom Initiative (NFI) established by President George W. Bush 10 days after he was sworn-in to tear down barriers to full community inclusion for people with disabilities, including intellectual disabilities. She thanked Committee members for participating in the meeting and expressed, on behalf of the President, appreciation for their service. Ms. Atwater then addressed several housekeeping items, including: 1) location of restrooms; 2) lunch arrangements and location of the cafeteria; 3) availability of a hard copy of 2009 Report to the President... left at the hotel front desk for citizen members upon arrival for check-in, and placed in the Meeting Resource Packets for ex officio members; and 4) arrangements for van transportation to the Newseum. Ms. Atwater turned the meeting agenda over to PCPID Chairman, Steve Rhatigan.

## **Opening Remarks and Approval of the Minutes and Agenda**

### **Steven C. Rhatigan**

Chairman Rhatigan greeted meeting participants and announced that: Stephanie Preshong Brown would be joining the meeting via audience conference; although Tom Reilly arrived at the hotel the evening before for the meeting, illness prevented him from remaining for the meeting; Billy Edwards' work schedule would prevent his participation; and Casey and Judy O'Halloran would be participating via audio conference. The Chair expressed his excitement about the 2009 Report to the President and stated his appreciation for the amount of input that came from ex officio and citizen members, and the work of the Project Officer, Laverdia Roach, and the writer, Dr. David Mank, and his team. Mr. Rhatigan noted that although Dr. Mank's morning presentation regarding the report will occur via audio conference, his PowerPoint is available and will be shown during the presentation; and that he will call in again during the afternoon session when members have had an opportunity to discuss the draft report and presentation.

Chairman Rhatigan expressed belief that the issue of refining 34 voices into one is what the writer and Project Officer have achieved on behalf of the Committee.

The Chair called for a motion to approve minutes of the September, 2008 quarterly meeting. Mr. Harris Hollin entered the motion, which was seconded by Mr. Eric Treat. Responding to the Chair's call for comments, Mr. Richard Balkus, ex officio representative from the Social Security Administration (SSA), referring to the statement on page 13 in previous minutes where he discussed the cost of living increase and the publication of the new Ticket to Work Regulations. He stated that he needs further clarification in terms of what he was talking about...adding that there's a possibility that we can't do it until October, he did not think the statement is correct. Ms. Kodie Ruzicka of the PCPID staff indicated that she would further check. Chairman Rhatigan asked if there were other comments. Hearing none, he called for and received approval of the minutes. Mr. Rhatigan then called for a motion to approve the meeting agenda. Eric Treat entered the motion that was seconded by Harris Hollin and approved by the full Committee.

**Review of the Writer's Role, Responsibilities and Methodology  
for Preparing the PCPID 2009 Report to the President  
David Michael Mank, Ph.D.  
Professor, School of Education  
Indiana University  
Bloomington, Indiana**

The Chair presented Dr. David Mank, who began by stating that it was an honor to work with the Committee and staff to write the Report to the President. He thanked Committee members for their thoughtful ideas, comments and input, noting that it was interesting to work to blend 34 voices [of 21 citizen members and 13 ex officio members] into one voice in the Report. He informed the Committee that Alice Porter, his friend and colleague, had been a great technical writer and that, together, they've come a long way in a short period of time. After sharing his pleasure with the title, *Report to the President: Dignity Through Employment*," Dr. Mank stated that 99 percent of the suggested edits received from Committee members were reflected in the draft, and proceeded to present several highlights of the Report, including:

The photograph of members with the President in the Oval Office;  
the Table of Contents; and  
the emphasis on quality, individualized, full-time employment.

The major sections of the Report, each with a statement of recommendations that pertains to that section:

The Executive Summary, with recommendations all together in one place;

the Introduction, setting up the circumstances of why employment is one of the most important things that can happen in any life, including the lives of people with intellectual disabilities;

descriptions of the Current Employment Status of People with Intellectual Disabilities, defined by unemployment, under-employment, and segregated rather than community settings;

the Evolving Policy and Legal Framework that directs the USA;

the Need for Comprehensive Implementation;

promising Employment Practices, and research indicating what we clearly know is possible, highlighting a few stories that help to setup recommendations;

building an Education, a Resume and Experience highlighting high school transition and through life, highlighting volunteer experience where appropriate,

highlighting post-secondary education as an important part, building not only the ability to work, but to invest in a career over time;

family and Systemic Supports, acknowledging that there are many, and that government programs have a direct effect on the extent to which individuals are working, have an incentive, or have a disincentive to work;

acknowledgments, with Committee's name, Ex officio and Citizen Members, contributors to the September 8, 2008 PCPID-ODEP Employment; and

forum, participants and other contributors.

Dr. Mank acknowledged that the heart of any such Report is the recommendations given by member of the Committee. Thus, he highlighted many of these suggestions:

- Encourage a Presidential Call to double the number of people with intellectual disabilities who are working in well-paid and integrated jobs in five years, beyond the 150,000 people estimated in community employment now.
- Create a national public awareness campaign to build on a new wave of employment expectations. Employment should be a part of an adult life.
- Achieve clarity of legislation and policy that focus on employment outcomes, with both incentives and working particularly with government agencies to make clearer statements about direction and the importance of employment.
- Build and invest in the President's New Freedom Initiative, specific to incentives to states, and try to understand how some states achieve greater success in promoting the employment of people with intellectual disabilities.
- Encourage employers to hire people with intellectual disabilities in good jobs. Invest with employers in recognition of that fact. This investment should involve the business community with incentives for employers. It should also create ways for people with intellectual disabilities and their families to be active and informed about these kinds of initiatives with employers.
- Promote employment, especially in the public sector where people with intellectual disabilities will have opportunities for quality employment in the same way that every other citizen has opportunities.

- Promote large-scale demonstrations in states in order to fully implement employment outcomes in larger geographic areas. Many examples of high quality employment outcomes tend to be in pockets rather than wide-spread in a geographic area.
- Look for opportunities for the federal administration to promote state Employment First agendas. That is, support initiatives or states that want to offer Employment First as a service and a support.
- Promote national and community service for young people, fully integrating young adults with intellectual disabilities. This would expand community service opportunities and build experience, a resume, and an education required for successfully employed in the future. The Corporation for National Community Service is currently doing this in some ways.
- Invest in the Education Act and the Rehabilitation Act, aiding the transition from education to future employment.
- Invest in the Rehabilitation Services Administration in order to feed agencies to promote transition focus.
- Address areas of incentives for individuals. Currently, because of asset limits and some of the structure of Social Security incentives, success or investment in the intellectually disabled can be made possible.
- Look at existing resources, Medicaid waivers and Social Security work incentives, and ask how you can emphasize community outcomes.

Note: Dr. Mank then reminded the Committee of a previous engagement that would take him away for a portion of the meeting. He will be leaving at 9:50 a.m. and rejoining the meeting at 2:15 p.m.

Ms. Laverdia Roach invited Members of the Committee who suggested edits, questions, or concerns to share those with Dr. Mank. Specifically, Mr. Harris Hollin was invited to share his observation. Mr. Hollin sent a message the previous Friday afternoon regarding accuracy in the first line of the second paragraph on page 7 of the most recent draft of the Report. Dr. Mank had already made the change based on this comment and apologized for the mistake.

Mr. Eric Cole suggested that another bullet be added to recommendation ten. This bullet would develop dissemination strategies to remind the public sector of the information, communication, and physical access standards in Section 255 of the Telecommunications Act and Section 508 of the Rehabilitation Act. Because it was not

submitted in writing, Dr. Mank asked Ms. Roach to e-mail this suggestion to him. He said that he would see how he could incorporate it.

Mr. Eric Treat suggested self-advocacy as the best option for transition. He also discussed the "Reach Beyond Greatness" program used in Wisconsin, asserting that this program should be brought into school districts. The curriculum was created by people with disabilities to become their advocate. Ms. Roach requested that Mr. Cole email that information to her as soon as possible, and she will make sure that Dr. Mank gets it in writing.

Dr. Sambhu Banik complimented Dr. Mank on his report, and had only one comment to make regarding the content. He could not see anything in the Report about the importance of assessment for employment; although, he did remember recommending that an emphasis be placed on the importance of assessment in Title II for appropriate adequate employment opportunities for people with intellectual disabilities. Dr. Mank pointed out that on page 24 under the rubric of discovering abilities is a process being called "Discovery" that includes a sentence on this topic. However, Dr. Mank agreed to see what could be done to clarify the issue. Ms. Roach suggested that Dr. Mank refer to the Forum papers in considering what can be done at this point. Dr. Banik's paper on *Assessment of People with Intellectual Disabilities for Vocational, Rehabilitative, and Employment Purposes* was a part of the Forum papers. So he should have that in his record. Ms. Roach offered to forward it again, if he did not.

Ms. Berthy De La Rosa-Aponte thanked Dr. Mank for his work on the report. She also posed the following question: in the letter, when we talk about being the final Report, is this the final Report, or is this the final Report under this President's Administration? Ms. Roach clarified that it will be the final report under this President's Administration. Ms. De La Rosa-Aponte asked if that should be stated more specifically in the report, and Ms. Roach thought such a statement might add clarity.

Ms. De La Rosa-Aponte also suggested a change to the letter to the President. In the third paragraph, when "the issue of real employment with compensation" is addressed, she proposed a substitution of the word compensation for something more like "equal pay." Compensation may not have the intended meaning. Chairman Rhatigan said they would discuss the letter later, during their session.

Next, Ms. De La Rosa-Aponte asked that, in the Executive Summary, the self-pity discussed by the President be added to the sentence that says "when people cannot work, they receive personal indignity, poverty and isolation." Dr. Mank thanked her for the input, but expressed concern that there was not sufficient time to completely rewrite the report. Chairman Rhatigan said that he would handle the rewrite on the issue. Ms. Roach deemed it unnecessary to add another statement. Ms. De La Rosa-Aponte acknowledged that the report she had was probably not the most recent version, and may not be up-to-date.

Chairman Rhatigan invited any comments from members regarding the outline, and none chose to do so. Dr. Mank then was excused from the audio conference by the Chairman to attend his other meeting and return at 2:15 p.m.

After Dr. Mank left, Ms. Zeppuhar informed the committee that she had been having some technical difficulties and was unable to get through in time to speak with Dr. Mank. The Chairman assured her that she would have the opportunity that afternoon, and she said that would be fine.

Chairman Rhatigan invited Ms. Roach to continue with the proceedings.

### **Review and Status of Activities to Prepare PCPID 2009 Report to the President Laverdia T Roach, Project Officer, PCPID**

Ms. Roach reviewed the status of activities to prepare the 2009 Report to the President. She began by thanking Dr. Mank and the members for respecting the process put in place to prepare the Report.

All members attended an ODEP (Office of Disability Employment Policy) and the PCPID Forum. The papers from that forum provided the basis for the 2009 Report to the President. Ms. Roach specifically thanked the ex officio representatives and Neil Romano, the Assistant Secretary of ODEP at the U.S. Department of Labor, for providing the fiscal support for the Forum. She also acknowledged the concern of Dr. Banik about the inclusion of his paper and assured him that material from that paper would be used by Dr. Mank.

Members received an opportunity for face-to-face dialogue with the writer on September 10th. Dr. Mank found the meeting very helpful.

All of the information sent to Ms. Roach last year by members of the committee on the topic of employment was packaged and sent on to Dr. Mank. As members view the report, they will see much of that information reflected in the draft.

Ms. Roach also emphasized Dr. Mank's exceptional work on the Report. She also thanked those who reviewed his documents and submitted comments in a timely fashion. Their timeliness allowed comments to be reflected in subsequent drafts. Increased attention will need to be devoted to the next draft since it will probably be the final draft. Members will want to review their comments, consider the comments made in this meeting, look at the report and begin thinking about voting approval. The sooner the Members are ready to approve the Report, the sooner the PCPID staff can submit the Report for review. Ms. Roach expressed the hope that this would be done in the next week or two. If that could be done, the Committee could have the final draft of the 2009 Report to the President by November 28, 2008.

Ms. Roach then asked if there were any questions. Mr. Stephen Hollingshead asked Ms. Roach if she was saying that she planned to vote on the Report before the final words

were in it. Ms. Roach responded that members should see the next draft as very close to the one on which they will vote. Any concerns with the drafts should be voiced at that time.

Mr. Hollingshead also asked Ms. Roach if she anticipated any problem for the different departments. Did she see anything controversial or should it get quick approval? Ms. Roach saw no real concerns. She expected that Richard Balkus would work with the members and writers to make the language more palatable to the Social Security Administration policies.

Ms. Linda Starnes asked Ms. Roach if “Official Declaration of Understanding” to Approve the 2009 PCPID Report to the President” on the schedule was the current discussion. If so, was that just a revisit? Ms. Roach explained that it was indeed the current discussion and that the Chairperson would speak more about that later.

For clarification, Mr. Balkus asked if November 28, 2008 was the date that the final draft of the document would be submitted to the Ex Officio Members for voting purposes. Ms. Roach confirmed that it was. She expressed hope that members will be talking to their policy people all along and will expedite the report to the best of their ability. The goal is to get the report out to the current administration by mid-December, although this is late. Otherwise, the White House may not have an opportunity to review it.

Mr. Balkus stated that he had already submitted a prior draft to some of the key components that will be involved in the review process. Thus, he did not expect difficulties. However, the voting may take a week to ten days to get through the components once there is a final draft to work with.

Ms. Roach acknowledged Mr. Balkus’ comments, stating that she appreciates the system within which they are working. When comments come from ex officio members, she immediately forwards them to the writer. If ex officio representatives will begin informally passing statements, issues, concerns, and recommendations by their policy persons, there will be nothing in the final draft that will surprise them or their policy persons.

Mr. Casey O’Halloran joined the meeting via telephone call.

Chairman Rhatigan invited the ex officio members to update the Committee on the developments in each area starting with Mr. John Vaughn from the National Council on Disability (NCD).

Mr. Vaughn introduced himself and explained that he looks forward to working with the Committee as the usual representative reached the end of his term. He felt that the Report was nicely done. The recommendation on transition service, getting more money and beginning at an earlier age, is similar to one of his organization’s recommendations.

At NCD, they put out an annual progress Report to the President and Congress. This year, it focused on current critical and emerging issues. This Report will come out in March at the Quarterly Meeting so there will be time for the new Administration to setup, and they will be able to hit the President and new Congress. The Committee may want to compose another letter to the incoming Administration as well. Mr. Vaughn also discussed the need for public awareness of intellectual disabilities and stated that the biggest issue today is societal attitudes.

Chairman Rhatigan thanked Mr. Vaughn for his contributions. The letter, which he recommended, will be discussed in the afternoon session. Mr. O'Holloran requested the chance to be part of that conversation since he was planning on writing a letter to the President as well. Ms. Atwater confirmed that the question would be taken up in the afternoon.

Following up with the comments of Mr. Vaughn, Mr. Richard Balkus mentioned his opportunity to attend the last quarterly meeting of NCD. This gave him the opportunity to discuss the research priorities of the SSA. The SSA staff are looking at the return-to-work issues and work incentives policy. The meeting gave helpful feedback.

Mr. Balkus then noted the following points:

The agency has issued a new strategic plan which is by far the best plan put out so far. It contains objectives for the disability programs. In the update, some highlights of those objectives are included.

Mr. Balkus expressed the hope of his group that legislation from the incoming Administration will help simplify the work incentive program for the public. Currently, the primary focus of work is the Disability Insurance Program.

The Supplemental Security Program needs improvement. This includes doing a better job with reporting and recording earnings in a timely fashion.

The agency's strategic plan calls for updating the medical listings.

An Occupational Information System needs to be developed to replace the Dictionary of Occupational Titles which is now outdated.

The Ticket-to-Work program has made some progress so far.

In the Benefit Offset National Demonstration One-for-Two Project, the final design has been accepted, and they are moving into the implementation stage. Mr. Balkus talked about why this program is important and eliminates the cliff effect.

Mr. Rob Sweezy arrived at the meeting and his presence was recognized by the Chairman.

Ms. Bellegarde gave updates from the Corporation for National Community Service (CNCS). The work continues to include an increasing number of individuals with intellectual disabilities. Their most recent large event was the National Conference on Disability Inclusion in National Service that was held last October in Alexandria, Virginia. Prior to that meeting, there was a Benefit Summit where administrators of their disability programs in states across the country were brought together. The purpose of the conference was to talk about the HEART Act and what it means for the future. The conference attendees discussed how should workers in Social Security and National Service be educated to work together and include people with disabilities in national community services?

The conference included the Spirit of Inclusion Awards. The award for distinguished leadership in disability inclusion across the country was received by Ollie Cantos. There was also an outreach to veterans with disabilities at the conference. The conference was very successful, beginning a dialogue that they hope to continue.

Ms. Margaret Schaefer came on behalf of Dan Sullivan, the Office on Civil Rights and Civil Liberties, and Claudia Gordon. Ms. Schaefer talked about the continuation of work in the area of individuals with disabilities and other special needs pertaining to emergency management. A publication in this area, *Emergency Management Planning for Special Needs Populations*, is now available on the Federal Emergency Management Agency (FEMA) website and has been well-received so far. They are still actively working to publicize this guide, especially through conference involvement and presentations to state and local governments.

Ms. Schaefer also discussed disaster services that her organization provides and gave examples of their involvement in preparation for hurricane Ike. Feedback was so positive after the storm that the organization was given a mission assignment by FEMA to be part of the Emergency Support Function or ESF – 14 Group. This will be a good opportunity to make sure that special need individuals are considered in recovery plans and communities are rebuilt to be accessible and inclusive.

Ms. Caffin Gordon, from the Department of Transportation (DOT), has been working closely with the Department of Homeland Security (DHS)/ Margaret Schaefer on emergency transportation for individuals with disabilities and special needs populations. DOT is responsible to ensure that all states, local governments, and tribal governments include persons with disabilities in emergency evacuations. The large number of entities responsible for this initiative has been a problem. It created confusion about which members should finance the actions of the group, causing delays in decisions which needed to be made quickly. Thus, they are now working on a policy initiative to ensure that, whenever issues arise, there will not be a question of financial backing. The most important thing will be getting the job done first and taking care of

financial issues afterwards. DOT has also signed the Memorandum of Understanding (MOU) with the Department of Labor to make sure that they continue to update the DisabilityInfo.gov website.

Ms. Mary Kay Mauren from Equal Employment Opportunity Commission (EEOC) informed the group that the Commission continues to update its Americans with Disability Acts ADA regulations and supporting guidance documents in light of the recent ADA amendments. They are still working on their initiative to increase employment for people with disabilities in the Federal Government as well. She referred to the presentation by Ms. Jo Linda Johnson back in September for more information on that initiative.

Mr. Stephen B. Hollingshead stated that there was nothing new in his area.

Mr. Ollie Cantos stated for the record that he was speaking as a Citizen Member who happens to work at the Department of Justice (DOJ) and happens to know what's going on there within the context of disability implementation. He was not speaking on behalf of Mark, since Mark did not give him authorization to do so.

Mr. Cantos talked about how the DOJ had recently incorporated the DOT's internal website on emergency preparedness for people with disabilities into its own emergency management efforts. They are working to incorporate efforts from the DHS in the area of emergency preparedness as well. The Civil Rights Division of the Justice Department also puts out articles focused on employment of individuals with disabilities. This will be coming out shortly.

Chairman Rhatigan asked any ex officios on the phone line to identify themselves, and there were no affirmative responses.

Ms. Starnes asked Mr. Cantos if he knew the date when the article would be coming out and whether there would be public access to it online. Mr. Cantos responded by saying that the article would be out by mid-January 2009. Past versions can be obtained in Microsoft word format by emailing [roxsand.c.devese@usdoj.gov](mailto:roxsand.c.devese@usdoj.gov). Individuals receiving the article may post, distribute, or send it.

(Morning Recess)

Chairman Rhatigan reconvened the meeting by introducing Mr. Bob Goldstraw to speak about the progress of disabilityinfo.gov.

**Disabilityinfo.gov Update**  
**Robert G. Goldstraw and Diana Zeitzer**  
**U.S. Department of Labor, ODEP**

Mr. Goldstraw talked about the bestowal of the Outstanding Partnership Award to the President's Committee because of the precise and helpful input which it has provided.

That same input has made for rapid advancement and improvement of the DisabilityInfo.gov website.

First, Mr. Goldstraw looked at a few statistics:

The number of visitors to the site was stuck at a little over 5,000 per day for a while.

It has recently increased by 33 percent to more than 6,000 visitors daily or almost 200,000 per month.

In 2007, the site had about 1.8 million visitors.

This calendar year it will likely have more than 2 million visitors.

The number of subscriptions has also increased dramatically to about 52,000.

This disabilityinfo.gov site should be used as a method for communicating. Contact Mr. Bob Goldstraw or Ms. Diana Zeitzer, directly, to add content to the webpage.

### **Presentation by Diana Zeitzer**

Mr. Goldstraw then turned the time over to Ms. Diana Zeitzer to go through the outline for DisabilityInfo.gov. The website organized by categories which are listed across the top of the page. In addition, there are resources at the state, local, and national levels. They would be happy to post any resources applicable to the site. Ms. Zeitzer encouraged anyone who had not previously done so to subscribe to the site in order to know what type of information it includes. Then, she gave some additional information about the resources on the website. In the near future, DisabilityInfo.gov plans to improve the search function on its site, making it easier to locate the intended materials.

Mr. Vaughn asked if they had reached out to organizations for the aging population. They had spoken with people from the American Association for Retired Persons (AARP) and gotten the link to DisabilityInfo.gov on the AARP Resource page; however, Ms. Zeitzer is still working on getting the link placed more prominently. They have spoken to a few other aging organizations like HHS, ALA and the CMS Caregiver Initiative as well.

It is more difficult to reach this target population since the term “disability” carries some stigma. Consequently, the aging population has not wanted to be part of the disability community and has not recognized themselves as part of that population in the past. This thinking has not necessarily changed in individuals, but organizations that represent the population have been more open to connections.

Mr. Cantos asked if information is already posted or prepared for posting on the disability related policies of the President-Elect as well as other disability related information having to do with transition. Although it may not be posted on the

website, they are preparing a transition Report for DisabilityInfo.gov which should include where we have been and where we hope to go.

The website still needs some work. It needs to be simplified and more user-friendly if the average person is supposed to be able to find what he or she is searching for. Currently, users find different information when using the categories to search and using the navigator. However, a tagging process is currently underway which should make the navigator more effective.

Since the staff of the website is small, they cannot keep up with every new development. Thus, they count heavily on contributors to bring them information and make sure the latest material gets on the site. Mr. Goldstraw requested that, as soon as the Report to the President for 2009 comes out, someone inform him. New information can usually be added within one day.

Ms. De La Rosa-Aponte suggested that a link be added to success stories about individuals with intellectual disabilities who have been self-employed. This would allow website viewers who want more information about the featured story to have easy access to that information. Mr. Goldstraw thought he could accomplish this by making a sub-folder under Self-Employment. This could turn into a "share your own stories" section where people can submit stories. He thought he would be able to add this section immediately.

The site will be redesigned soon with the intention of making it more interactive and consistent with big interactive sites and social networking sites. Recent changes with government websites are allowing movement in that direction. Eventually, they want the site to be more customizable, so that individuals will not have to see anything that does not interest them.

Mr. Goldstraw expressed some brief concerns about Web 2.3 since he is familiar with Web 2.0. Mr. Eric Cole proposed a solution and volunteered to assist Mr. Goldstraw in setting everything up. Mr. Cole thought they could connect to other search engines and pull from those search engines as well. He also felt that the ODEP publication was fabulous and should be available online if it was not already available. Ms. Sue Picerno said she would check into that. There is an electronic version being put together, but she did not think there was one available online. As soon as that becomes available, Ms. Zeitzer will put it up, and Mr. Cole will disseminate it to their constituencies.

Ms. Linda Starnes asked about the parameters in place for the content on the website: what is allowed to be put onto the site? Are the guidelines the same for the local level? Has anything evolved since this was last discussed? The parameters have not evolved. About half of the sources come from .gov websites. The rest were .org, .edu, and .us. This does include some faith- and community-based resources. When it gets down to local governments, most of the resources for those with disabilities do not come from

the Federal Government or even state government. The only restriction is the exclusion of profit-making entities.

Because the website excludes profit-making entities, Ms. Starnes questioned the previously discussed section regarding self-employment. The featured individuals would be making a profit. Up to this point, the problem has been dealt with by having a warning pop up that tells the person that the site they are about to visit is not necessarily supported or endorsed by the government. The exact rules, however, are still being figured out. They should be able to put up success stories that do not link to a particular company or business. They still have not been told whether they can link to .coms.

Ms. Starnes added the suggestion that anyone who has a chance to speak in public might spread the word about DisabilityInfo.gov, letting groups know what a great resource the website can be.

Mr. Casey O'Holloran suggested employment coaches as a possible addition to the site

In critique of the website, Ms. Mary Ellen Zeppuhar added that the links could be a bit more general and user-friendly. She also presented some ideas for the redesign of the website. Mr. Goldstraw expanded on her ideas, explaining that the website needs to be easy to navigate. Eliminate anything about the site that impedes, among other people, people with intellectual disabilities from finding what they're looking for. If it takes a long time for a person to find what he or she is looking for, the site is useless.

There are many things that they have planned for the redesign that they expect to implement in the first quarter of next year. This will include the removal of irrelevant text. A quick link section will be added to the home page. Stories of individuals with disabilities with great achievements will be featured.

Mr. Eric Cole brought up a product called Work World ([workworld.org](http://workworld.org)) with a number of features and a health feature available at no cost. It quickly tailors results to your geographic region. He suggested that they might want to add something like this to DisabilityInfo.gov. Mr. Goldstraw agreed to bring the idea to the information technology team.

Ms. Mary Ellen Zeppuhar asked if the website was also accessible for people who use screen readers and if it filled all those requirements. Mr. Goldstraw assured her that they are. However, since the site is a web portal, the connecting sites may not be accessible. In order to help this problem, they could make an effort to lead the user only to sites that meet the requirements for accessibility. However, that type of restriction would eliminate a lot of the content. They can make the website completely accessible, but not all the sources from which the website pulls.

Ms. Sharman Word Dennis inquired whether the site talked yet. Unfortunately, the site does not talk. Mr. Goldstraw did speak with the information people about it.

Mr. Ollie Cantos asked if there is information on the website about how to write accessibly for people with developmental disabilities? He knew that such a guide existed. Ms. Zeitzer said she would check online to see if she could find the publication. If it's available online, it will be up. Mr. Cantos will email the link for the guide he talked about.

There is an excess of material on the website. One goal right now, as mentioned by Mr. Goldstraw, is to go through everything on the website and dump what may not be of the greatest use.

Mr. Hollingshead discussed a strategy to get the websites which link into DisabilityInfo.gov to become accessible. Since DisabilityInfo.gov generates hits for the sites, they can control which sites get more hits to some extent. The content providers can then be pushed, once they realize that this website is effecting how many hits they receive, to invest in accessibility.

Members discussed various ways that the website might be improved. For example, the website's search engine could scroll other connected search engines and return those results as well.

Mr. Goldstraw closed the presentation with an invitation for continuing comments to improve DisabilityInfo.gov. Chairman Rhatigan dismissed the participants for lunch, to reconvene at 12:45 p.m.

(Recess for Lunch)

## **AFTERNOON SESSION**

Chairman Rhatigan reconvened the meeting and introduced the itinerary for the following hour. The meeting was instructed to split into four Focus Groups and discuss thoughts on what they heard from Dr. David Mank. The Chairman informed members that, after an hour, there would be a break and Dr. Mank would rejoin the group.

The Focus Groups met and reconvened to Report out

### **Focus Group Report on Preparation for Employment**

Ms. Linda Starnes reported for the sub-group dealing with Section 4, ability and education, a resume, and experience. The sub-group members began by making a record of all the typos that were found in the draft. Then, they looked more globally for comments regarding content or larger pieces of formatting. Following are some of the review comments and suggested corrections:

A problem was found with the use of the acronym “ID” in place of “intellectual disability” without specifying the meaning of the acronym.

There needs to be a disclaimer on the usage of “mental retardation” and “MR,” explaining that the two are synonymous with intellectual disabilities. The older term is being used in that particular instance.

The vignettes used need disclaimers. Many of the individuals in the vignettes have other conditions, which are mentioned, in addition to their intellectual disabilities. For example, autism and traumatic brain injury are both discussed. Unfortunately, the text does not clarify that these conditions are not synonymous with intellectual disabilities. Since the vignettes came prewritten, a disclaimer is necessary to clarify the message.

On page 28, there is need for rewording of the last sentence of the first paragraph. The sentence should read, “individuals with intellectual disabilities are ready to work when appropriate technological and other supports are provided as needed, to facilitate ongoing employment career success, and economic self-sufficiency.” The intent is not to give the impression that people with intellectual disabilities could only work when provisions were made for them.

On page 28, under “Transition From School to Employment,” at the start of the second paragraph where it says “leaving high school,” the final part of that sentence is left out. This will exclude, “up to age 21 where graduating from special education programs.” Not everybody with an intellectual disability graduates with a special education diploma. Instead, state that “no less so for young people with intellectual disabilities.”

On page 29, there is need for a small piece of data to go with the text about post-secondary education.

On page 30, there is need to use wording that will strengthen the sentence that talks about the Higher Education Opportunity Act.

Under “Recommendation” on page 30, the wording needs to be changed under the bullet. The phrase “of all race and ethnicity,” will become “of all ages and backgrounds” since even very young people, with or without a disability, can be involved in volunteerism.

Finally, they need to do some formatting in the section by moving the summary up before the “Recommendations” as it is in the other sections.

## **Focus Group Report on Public Awareness**

Ms. Mary Ellen Zeppuhar discussed this group's review of the section:

They discovered a problem with redundancy between the first paragraph on page 5 and the first paragraph at the top of page 7.

On page 9, Recommendation 3, sub-bullet 2 when it talks about developing a unified statement for employment for people with intellectual disabilities, it should probably be the Department of Education (ED.Gov) versus the Department of Energy (DOE).

The stress needs to be on Reports of public awareness in general, going beyond the issue of employment.

They would like to look into cross-referencing the recent NCD Report on transition with recommendation 11.

Another correction needs to be made on page 22, in the last sentence of the last paragraph, under the section heading "Coming Into the Mainstream." The report talked about technology solutions and assistive technology. This needs to include a sentence that says something about services provided by programs, such as the Job Accommodation Network (JAN). This organization helps employers to determine practical, low-cost, and sometimes no cost accommodations to help support workers with intellectual and other disabilities. A toll-free number and a website should also be included. Accommodations do not necessarily have to be technology-based or expensive.

Ms. Zeppuhar agreed to email corrections to Dr. Mank immediately.

## **Focus Group Report on Employment Supports and Benefits**

Focus group members also suggest that the Report reference and acknowledge the existence of the new strategic plan of the Social Security Administration in a way that was not offensive.

Highlight one of the stories from the report. It would be left exactly where it is, but also printed on the inside of the front page of the Report. As the Report opens, that story sort of sizes it up. The Microsoft story and the Starbucks story were both recommended as possible options.

Since the Report may be read after the 20th of January, 2009, use the words "the intent of the New Freedom Initiative" or refer to the New Freedom Initiative as an Executive Order, better known as the New Freedom Initiative. This should give it a more neutral standing.

## Focus Group Report on Research

Mr. Harris Hollin started by commenting on the success of the procedure used to produce the Report and how easy it was to work with. He also thanked the Committee for cooperation and help received. Mr. Hollin then made two immediate suggestions:

In the future, the drafts of meetings or the Report should be dated so that recipients know which is the most recent.

Drafts should be tracked so that the entire document does not need rereading for every change.

Next, Ms. Mary Margaret Sharp-Pucci expressed pleasure with the way the research fit into the Report on employment as a whole. Most of the contribution of the Research Focus Group can be found on page 14. Emphasis is placed on the genetic and syndrome-specific intellectual disabilities which make up 30 percent of intellectual disability populations as a whole. This section was also able to highlight individually tailored supports and strategies. The adaptation of environments came out of that research section

Research permeated the rest of the report also. Programs, recommendations, or strategies that are effective are primarily based on research. In addition, they were able to form a task force based on a research question: what factors differentiate between the top states and the bottom states?

After Ms. Sharp-Pucci finished, the Chairman proposed a ten minute break. Before the break, Ms. Laverdia Roach requested that each of the Focus Group Chairs email their to her, so that she could be sure that all suggestions are received and communicated to the writer as soon as possible. She then reminded members that the date was the November 19, 2008 and they get the final the November 28, 2008.

(Afternoon Recess)

Chairman Rhatigan reopened the session and pointed out that Dr. Mank was back on the phone. He then briefly discussed the proceedings that took place during Dr. Mank's absence.

Dr. Mank was told that Ms. Roach would have comments coordinated with the sections in the existing draft by Monday. Dr. Mank requested that he have the comments by Friday instead. Ms. Roach said that she would send the rewordings as soon as she received them from members no later than Monday. Ms. Linda Starnes' corrections will definitely not be in until Monday. However, he should receive some corrections Friday with which to start the rewording. Ms. Roach would not be sending anything after Monday.

Dr. Mank expressed a concern about the deadline. Ms. Roach assured him that she would get him the information in the area of Employment Support the next morning. She would have the information on Preparation to him as soon as Ms. Starnes got in front of a computer, which they would try to make that happen that day.

Mr. Cole thought he would be able to get his report to Ms. Roach by that evening. Ms. Roach thought she would be able to get the information out to Dr. Mank by no later than noon the next day.

For the benefit of Dr. Mank, the sub-committees briefly presented their conclusions again:

Ms. Starnes asked if “through,” in the title of the Report, was meant to be capitalized. Ms. Roach said that she would look into the question and get that information to Dr. Mank the next day. The consensus of the Focus Group Members was that they wanted the word capitalized.

Instead of putting “ID” in the report, Dr. Mank suggested that “intellectual disability” seems to follow better.

A disclaimer needs to be copied from the 2008 PCPID Report and inserted into this draft of the report, explaining the usage of the term “mental retardation” or “MR.” Ms. Roach will email the 2008 Report to Dr. Mank so that he can make this correction. There is already a brief explanation of this usage at the beginning of the draft, where it talks about definitions used in the report, but that explanation is not believed by most of the Focus Group members to be sufficient.

Disclaimers are also to be attached to each of the vignettes, so readers can understand that each of the featured individuals does have an intellectual disorder even if there are additional conditions mentioned. The Starbucks story may need to be excluded in this case because the individuals involved would prefer not to be identified as intellectually disabled. Dr. Mank will check with the people that know her family.

Ms. Starnes observed that a formatting error should be corrected. In Section 4, the Summary section was listed at the end on page 31 after recommendations. However, in other sections of the Report, the summarizing came just prior to the Recommendations.

Ms. Starnes brought up the previously mentioned issue on page 28 in the last sentence of the first paragraph that discusses the readiness of those with intellectual disabilities to work. She presented her rewording, and Dr. Mank said that he would have to look at it in the context of the paragraph. Ms. Roach and Dr. Mank will be in touch regarding this rewrite.

Another issue on page 28 can be found under the “transition from school to employment” at the beginning of the second paragraph. They would prefer to simplify the sentence by saying “no less so for young people with intellectual disability” because not everyone goes all the way to age 21.

Mr. Hollingshead also made another suggestion on the same page, a few sentences up. He felt that the word “all” should be deleted from the sentence that reads, “all individuals with intellectual disabilities are ready to work.” Ms. Starnes informed him that it had already been deleted.

Ms. Starnes asked if anyone had researched whether youth with intellectual disabilities who receive post-secondary education are more likely to be competitively employed. Along the same lines, they might highlight the fact that youth with intellectual disability are perhaps even less likely to make it into post-secondary education than others. Dr. Mank informed her that youth with intellectual disabilities are included in broader studies, but are not disaggregated. Thus, they cannot yet be examined separately.

The sentence on page 30 about the Higher Education Opportunity Act needed rewording. They might want to stress the limited amount of data available because the Higher Education Opportunity Act and the research data are both so new. In the next report, they may want to look at whether or not it made a difference to have these opportunities. Dr. Mank thought that the current point was to just get attention to the issue.

Under Volunteering, in the middle of the first paragraph, there is a sentence talking about how volunteering can confer social, emotional, and even physical benefits consequently “being.” The word being needs to be removed.

Titles and organizations were listed for the presenters in some of the draft, but were excluded in the latest draft. Since not all the presenters were mentioned in the reference section, they should list the name, the title, organization, and city/state of the presenters. Ms. Roach informed Dr. Mank that this information was available on the Open Forum Agenda and volunteered to email that document to him the next day. The presentation title still needs to be listed along with the other information.

Ms. Starnes gave examples of a few places that require changes:

The References at the top of page 39 had a few lowercase “I”s that did not belong. This might be garbage data that got thrown in, a printing issue, or a messed up italics code. No problem existed in the electronic version. The same thing happened with question marks and URL listings.

On page 7, under the definition of intellectual disability, in the fourth paragraph, near the middle of the paragraph, it refers to a list of syndromes as cited above when the citation is actually below.

Ms. Starnes will send a written report of her comments.

Mr. Ollie Cantos offered only one suggestion:

In the title, the proposition should not be capitalized. Ms. Zeppuhar suggested that they see if the PCPID staff had some kind of style manual to follow. Ms. Roach said that she did have a manual and would report her findings to Dr. Mank. Ms. Bazilio-Bellgrade thought the title looked better with a capital T.

Will Tienken gave the following comments on the Supports and Benefits section:

There was a reference to the statement that was made in the Agency's recently reviewed strategic plan. Basically, it is a commitment to making Return to Work easier, and simplifying the rules. Mr. Tienken thought they should add a brief statement in order for the reference to make sense. He will send a few sentences to Ms. Roach early the next morning. In the first paragraph after the bullets on page 33, there is a place where it would fit into the Report. The key thing was to add a reference to the strategic plan being a new document and highlight it.

They should lift one of the personal vignettes. The specific one to use is open to discussion. The vignette would be inserted inside the front cover as a way of personalizing the Report. Dr. Mank informed him that starting with a story before any other information suggests that the story is the most important thing.

Ms. Zeppuhar mentioned the fact that this Report will be the last one for the current President, but also the first Report seen by the new President. What should the President know, look at first, and focus on? The focus should definitely be on employment. He may start with an attitude that people with intellectual disabilities cannot be employed and need other kinds of support, but the Report may help that if it stresses the idea that they can be self-sufficient and have a job.

Ms. Roach pointed out that the Report will not automatically go to the new President. If that is what the Committee decides to do, they must transmit the request in the form of an Action Memo through the Secretary to the new President.

Ms. Zeppuhar asked if the Report becomes part of the public record, making it possible that the new President would see it. Ms. Roach said that it does become part of the public record, but thought it is unlikely that the new President would read it with all the items on his agenda.

Chairman Rhatigan said that they would discuss this further at some point.

Mr. Eric Cole cited the following four general recommendations from the Focus Group on Public Awareness:

- 1) Under Recommendation 10, add a bullet along the lines of “develop dissemination strategies to reinforce to the public sector the communication, information, and physical access standards in Section 255 of the Telecommunications Act and the Section 508 of the Rehabilitation Act.”
- 2) Cross-reference Recommendation 11 with the recent NCD Report on Transition.
- 3) On pages 5 and 7, consider revisiting the definition of “ID” and whether or not it is redundant. Some of the verbiage was the same on page 2.
- 4) On page 9, Recommendation 3, under the second bullet, “energy” is reference. It looks like this was meant to say education. It references DOE, but was meant to reference the Department of Education.

Mr. Hollingshead had one suggestion in the area of Research. He thought that, on page 12, the rhetorical tone should be lowered a little bit. In the third line, he wanted to omit the word “undeniable” where it said “we make the undeniable argument.” No one objected to this idea.

Chairman Rhatigan, once again, raised the issue of moving a vignette from the text to the inside of the front cover. He wondered if there was a way to have a positive success story at the front without focusing or the presumption of a focusing on that particular vignette as the scope of the entire Report.

Mr. Hollingshead thought that since the stories use only the first name, they are adequately nonspecific. These are clearly examples from which the Report is not necessarily extrapolated. In addition, these examples appear in neat boxes throughout the text. If they remain uniform, a viewer can easily flip through and see that the story at the beginning fits into this category. In Mr. Hollingshead’s opinion, starting with a story is a great idea.

Chairman Rhatigan called for an informal vote on the question, but before the voting commenced, Ms. Bazilio-Bellgrade added another solution to consider. They could add a lead-in sentence before the story, stating that this is one example of many which can be found in the text exemplifying the message of the Report. Mr. Hollingshead was concerned that her approach was a little too self-conscious and would detract from the rhetorical idea as a result.

Chairman Rhatigan again called for a vote on whether a vignette on the inside front cover would be a positive thing. The majority voted in favor, and the Chairman

confirmed to Dr. Mank that they would go ahead and include a vignette in the inside cover.

Chairman Rhatigan felt the story with Dan and Microsoft was the most compelling. Dr. Mank planned to suggest the same story.

The story will be featured in both the inside of the cover and in the text of the Report.

Ms. Sharman Word Dennis proposed the idea of featuring PCPID member Casey O'Holloran's bio on the inside cover instead. He is employed, young, lives alone, and is on the Committee. Mr. Hollin supported this idea and made it a motion. The motion was seconded by Mr. Eric Treat.

Ms. Claudia Gordon reminded the Committee of concerns raised by Ms. Roach earlier and wondered about possible legal implications or a conflict of interest. Should the Committee look into the possibility first? Mr. Hollin saw no conflict of interest since there would be no economic benefit to Casey. His relationship with the Committee is pro bono, unless you consider the rate of pay we're getting as being worthy of a conflict of interest.

Mr. Tienken thought it was a great idea to use Casey's story, and he asked that Dr. Mank write it out with the same tone as his other bios and put it on the inside cover.

Ms. Dennis suggested that Casey's story could replace Courtney's story since Courtney's story had a problem.

Ms. Roach said that she would send Casey's story to Dr. Mank.

Chairman Rhatigan asked if there was anymore discussion desired before the Committee was ready to vote on the topic. Ms. Starnes chose to continue the discussion. She wanted the vignette of the gentleman at Microsoft to have a mirror vignette on the back inside cover. This end piece would give some symmetry. One problem with this proposal, raised by Mr. Hollingshead, is that it would highlight two Down syndrome stories.

Chairman Rhatigan again asked if there was any further discussion needed. Dr. Banik related how he found Casey's story very compelling. He felt it would also inspire others with intellectual disabilities to apply for membership in the PCPID.

Mr. Hollingshead thought that the story should be framed in the same way as all the other stories. That is, the Committee membership should not be mentioned explicitly and he should be referred to as just Casey. Mentioning his full name and position would diminish the value of the story as a teaser.

Ms. Bazilio-Bellgrade asked for clarification. Mr. Hollingshead was indeed suggesting that they not mention that Casey is a Member of the PCPID. Ms. Bazilio-Bellgrade disagreed with this proposal because she felt it was important to give examples of leadership and volunteering on boards. If it looks like they are talking about themselves, the material will not have the desired rhetorical punch. Maybe they should return to the idea of having the Microsoft story at the beginning because it needs a more generic story. Ms. Roach agreed with him.

For a vote, Chairman Rhatigan presented the motion on Casey's story without the discussion on his Membership. This motion passed. He then proposed a second vote on whether to include the PCPID and a description in this account.

Mr. Cole proposed a different motion. He thought that they should let Dr. Mank work up the story first. When it is complete, they can decide which story would be best for the inside cover. Chairman Rhatigan thought the decision needed to be made right then because of time constraints. Mr. Tienken suggested that Dr. Mank could write up Casey's story, culminating in with PCPID. When the story is printed on the cover, the part about PCPID could be left out. It would only be included in the text of the Report.

Dr. Mank inquired where Casey's story would go in the Report. The story could be used if a replacement is needed for Corey or in addition to the three already present.

Ms. Roach expressed belief that it might be better to put the Microsoft story on the front cover and put Casey's story on the back cover with the PCPID statement. However, it was suggested that it might be a problem to have two Down syndrome examples on the covers. Ms. Roach thought that people would not focus as much on the syndrome as they would on the impressiveness of the stories in the vignettes. This is important because impressing employers is the goal. Mr. Hollin felt that the frequency of Down syndrome cases compared with other syndromes warrants the use of two examples.

The Microsoft story will be put on the front cover and Casey's story will be featured on the back.

Mr. Cole suggested that they might refer to Casey as an individual with an intellectual disability rather than having Down syndrome. However, Mr. Hollin felt that this was unnecessary. It was then proposed that his syndrome be specifically mentioned at the end of the story rather than at the beginning of the story.

Another motion was proposed. This motion was to supersede the previously approved motion and place Casey's story on the back cover of the account.

The Microsoft story will go on the inside of the front cover and the Casey story will go on the back cover. Ms. Roach will get Judy's write-up of Casey's story which should be available shortly. She will pass that on to Dr. Mank. This plan was voted on, and there was a consensus.

Chairman Rhatigan asked if there were any further issues. Mr. Hollingshead wanted Casey's story added somewhere in the text in addition to the back cover. Dr. Mank asked that he be able to see it first.

Chairman Rhatigan invited any further comments. There was no response.

Mr. Gordon inquired where the picture would be put in the report. It was suggested that the picture be put on the page with a description of the Committee. The intent was to put it up front. Mr. Gordon had no preference as to the placement. This will probably be featured somewhere on pages three, four, or five.

### **Final Discussion of Pre-printed PCPID 2009 Report to the President PCPID Ex Officio Representatives and Citizen Members**

Mr. Tienken pointed out that they had all of the Secretaries as ex officio. He wondered if they were going to put in any of the representatives, thank you notes, or acknowledgment in the Report since the version he received just had the ex officio representatives. Ms. Roach informed him that the representatives have never been included in the past. Mr. Tienken wondered if they should include a special thank you in the Report. Ms. Roach thought they might be able to begin the acknowledgment section by recognizing the service of ex officio representatives.

Ms. Roach will send the names of the representatives to Dr. Mank for inclusion. These names will be put in as they are featured on the roster: "Ex Officio Member represented by." Dr. Mank will set it up stylistically however he would like.

Chairman Rhatigan thanked Dr. Mank for his contributions. Dr. Mank requested that everyone have their information to him in a timely manner, and Chairman Rhatigan assured him that they would.

### **Official "Declaration of Understanding" to Approve PCPID 2009 Report to the President PCPID Ex Officio and Citizen Members**

Chairman Rhatigan took a few minutes to discuss the unique situation the Committee was in with a new administration. They ought to be presumptuous and prepare this Report to go to the new Administration as well. This would mean new transmittal letters as of January 21st. The Chairman assumed the responsibility for writing the new letters. The style would need to be changed and then transmitted from the new Secretary of Health and Human Services. This topic is important to others besides the members of the Committee.

Mr. Eric Cole explained that, in the Public Awareness Focus Group, members discussed sending a letter to the Secretary and on to the President as a final push to have previous Reports released. They would specifically inquire about the 2000 Report on dental care, the 2007 Report on asset development, and the 2008 Report on FAS and FASD in

addition to this current Report. He felt that it would be appropriate to mention the time and cost invested to produce these reports. This letter would be in addition to the letter transmitting the Report.

Mr. Cantos felt that they work really needs to be done to get these Reports released under this Administration by emphasizing that this is literally the last chance. They need to respectfully and strongly ask the President or the White House to allow them to publish these Reports. At least \$2.4 million in time, staff, resources, and other assets has been invested in these reports.

If they are still unable to get the Reports published, they may be able to release the documents as findings of the Committee or something in that vein. This can be done under the charter which allows them to release other documents as they deem it necessary. Ideally, however, they would want to do it under the seal of the President as it has been done in the past. If they cannot get it published as it has been before, they should still release it under this Administration by January 20<sup>th</sup> so that it is on record that this Administration made recommendations. President Obama can look through the work that has been released and move forward with suggestion.

Chairman Rhatigan approved of the effort to get the Reports published. He will work with Sally, Laverdia, and Ollie to write the appropriate letter. However, he was not sure about the alternative plan which Mr. Cantos proposed.

Mr. Tienken questioned whether they should discuss the New Freedom Initiative if they wanted the Report to go to the new Administration. He thought that mentioning the New Freedom Initiative would neutralize any political interpretation of this Report for the new Administration. Chairman Rhatigan will work with Ms. Roach, Sally, and Ollie to come up with a letter that would transmit it properly. Ms. Roach asked that Will email her the basics of how it should be worded and set up.

Chairman Rhatigan and Mr. Balkus discussed the CMS issue and whether it was clarified. Mr. Balkus was not quite sure how Social Security would fit into that recommendation.

Ms. Roach asked if Mr. Balkus would find it helpful to do some bullets indicating how he thought the rewording ought to be. However, he stated his preference that someone from HHS and CMS pick up on that. Chairman Rhatigan felt it clarified the situation when informed that it refers to 1915 and not just broadly.

**Information Sharing  
Committee Members, Constituency Group  
Representatives and Citizen Members**

Chairman Rhatigan invited members to talk about Information Sharing.

Mr. Eric Cole informed the group about some of the things that have been going on in the Public Awareness arena. He thanked the staff of the Committee which has been working on getting past publications in an electronic format that can be posted on the website. He also thanked Mr. Cantos.

Ms. Starnes brought up a discussion about remaining in contact via friends of the PCPID. She talked about Fred Krause, former PCPID Executive Director, providing that kind of activity, but she has not tapped into that yet. She asked Laverdia to shed some light on the kinds of things that are done through his volunteer service.

Ms. Roach explained the background of Fred Krause. He is a former director of the President's Committee on Mental Retardation (PCMR) who established the Friends of PCMR Group. Ms. Roach will contact him to learn about the status of the group and their recent activities. The group is very supportive of the PCPID in a non-financial way. In order to carry out projects, they depended on co-sponsorships, usually from sister agencies. The PCPID is not allowed to raise money and they cannot accept money because they do not have gift authority.

Ms. Starnes said that she would be interested in receiving information from Laverdia. She would like to see the new National Council on Disability (NCD) Reports or anything like that which might be missed.

Ms. Starnes also reminded the group that the Annual Access Ministry Summit at McLean Bible Church, the large national conference on faith and disability, will be held on March 20th and 21st. She and Mr. Sharman Dennis will both be speaking. Lewis Solomon, the pastor of the church, was a former Member of the PCPID. These are the types of things that she would like to be informed about, if that no longer happens through the Friends of PCMR.

Mr. Hollingshead suggested that Eric Cole could setup a simple association using a tool like Linked In. Then, people can ask to be invited to the group. Mr. Cole or Ms. Roach could be the administrator. The group will pop up when people search intellectual disabilities. There could be discussions between group members. They could expand the network from current the Administration to earlier administrations, parents, and others.

Mr. Cole inquired whether Linked In was the best platform to use. Ms. Zeppuhar thought that a link on DisabilityInfo.gov might also be helpful. It might make things easier for parents.

Chairman Rhatigan expressed certainty that the group would think of a way for members to keep up with one another.

Mr. Cole said that he would work with the staff on that project. If anyone has questions, they can e-mail him.

Ms. Atwater reviewed a few housekeeping items for the next day. The Awards Ceremony given to recipients in memory of Dr. George Bouthilet was the following day. The ceremony would be starting at 8:30 a.m. Individuals were asked to report to the same room as the present meeting around that time. At about 9:30 a.m., they will leave for the Newseum. They will be there for a few hours. Those on the phone may call in from 8:30 a.m. to 9:30 a.m. if they wish to participate. However, participation in the ceremony is not mandatory.

Ms. Atwater took a minute to recognized the staff of the PCPID and thank Ms. Kodie Ruzicka who would be leaving the staff shortly.

Chairman Rhatigan called for any final comments. When no one responded affirmatively, he thanked Ms. Sally Atwater for her work with the committee. She served for seven and a half years.

With that, Chairman Rhatigan recessed the PCPID quarterly meeting and stated that it would reconvene on November 20, 2008, at the Herbert H. Humphrey Building, Room 705A, at 8:30 a.m.

### **Action Items**

#### **November 19, 2008 Quarterly Meeting**

Ms. Kodie Ruzicka will check Mr. Richard Balkus' statement on page 13 of the minute. The statement needs further clarification as to what Mr. Balkus was discussing. It should include the possibility that they cannot have it done until October. Unless this is changed, Mr. Balkus will consider the statement to be incorrect.

Ms. Laverdia Roach will email Mr. Eric Cole's suggestion that another bullet be added to recommendation ten. This bullet would develop dissemination strategies to remind the public sector of the information, communication, and physical access standards in Section 255 of the Telecommunications Act and Section 508 of the Rehabilitation Act.

Mr. Eric Cole will email information to Ms. Roach as soon as possible about the "Reach Beyond Greatness" program used in Wisconsin. Ms. Roach will make sure that Dr. David Mank gets this information in writing.

Ms. Roach will forward a copy of Dr. Sambhu Banik's paper on *Assessment of People with Intellectual Disabilities for Vocational, Rehabilitative, and Employment Purposes* to Dr. Mank.

In the Executive Summary, the self-pity discussed by the president needs to be added to the sentence that says "when people cannot work, they receive personal indignity, poverty and isolation." Chairman Rhatigan will handle the rewrite on this issue.

The staff of [disabilittinfo.gov](http://disabilittinfo.gov) will work to simplify the website and make it more user-friendly.

As soon as the Report to the President for 2009 comes out, PCPID will inform Mr. Robert Goldstraw so that he can add it to the site.

Mr. Goldstraw will immediately add a link to the DisabilityInfo.gov website covering people with intellectual disabilities that have successfully been self-employed. He will accomplish this by making a sub-folder under Self-Employment.

The staff of disabilityinfo.gov will redesign the site soon with the intention of making it more interactive and consistent with big interactive sites and social networking sites.

Mr. Eric Cole volunteered to help Mr. Goldstraw setup a connection to other search engines and pull from those search engines as well.

Ms. Sue Picerno will check whether the ODEP publication is available online. As soon as that becomes available, Ms. Diana Zeitzer will put it up on disabilityinfo.gov, and Mr. Cole will disseminate it to their constituencies.

Any member who has the chance to speak in public should spread the word about DisabilityInfo.gov and what a great resource the website can be.

During the redesign, the staff of DisabilityInfo.gov will remove irrelevant text, add a quick link section to the home page, and feature stories the achievements of individuals with disabilities.

Mr. Goldstraw agreed to talk to the information technology team about adding a product like Work World (workworld.org) to DisabilityInfo.gov.

Ms. Zeitzer will check online to for a publication which explains how to write accessibly for people with intellectual/developmental disabilities.

Mr. Ollie Cantos will email the link for the guide he discussed which explains how to write accessibly for people with intellectual/developmental disabilities.

Members of the Committee will continue to give feedback to improve DisabilityInfo.gov.

Ms. Mary Ellen Zeppuhar will email the following corrections to Dr. David Mank immediately:

They discovered a problem with redundancy between the first paragraph on page 5 and the first paragraph at the top of page 7.

On page 9, Recommendation 3, sub-bullet 2 when it talks about developing a unified statement for employment for people with intellectual disabilities, it should probably be the Department of Education versus the Department of Energy.

The stress needs to be on Reports of public awareness in general, going beyond the issue of employment.

They would like to look into cross-referencing the recent NCD Report on transition with recommendation 11

Another correction needs to be made on page 22, in the last sentence of the last paragraph, under the section heading "Coming Into the Mainstream." The report talked about technology solutions and assistive technology. This needs to include a sentence that says something about services provided by programs, such as the Job Accommodation Network (JAN). This organization helps employers to determine practical, low-cost, and sometimes no cost accommodations to help support workers with intellectual and other disabilities. A toll-free number and a website should also be included. Accommodations do not necessarily have to be technology-based or expensive.

Each of the Focus Group Chairs will email their Reports to Ms. Laverdia Roach, so that she could be sure that all suggestions are received and communicated to the writer as soon as possible.

Ms. Roach will send the comments as soon as she receives them from members no later than Monday.

Ms. Roach will get Dr. Mank the information in the area of Employment Support the next morning.

Ms. Roach will have the information on Preparation to Dr. Mank as soon as Ms. Linda Starnes gets in front of a computer, which should happen that day.

Mr. Cole thought he would be able to get his report to Ms. Roach by that evening.

Ms. Roach thought she would be able to get the information out to Dr. Mank by no later than noon the next day.

Ms. Roach will look into whether "through" should be capitalized in the title of the Report and get that information to Dr. Mank the next day.

Ms. Roach will email the 2008 Report to Dr. Mank so that he can copy the disclaimer and inserted it into the current draft of the report.

Ms. Roach and Dr. Mank will be in touch regarding the rewrite of the last sentence of the first paragraph that discusses the readiness of those with intellectual disabilities to work.

Titles and organizations were listed for the presenters in some of the draft, but were excluded in the latest draft. Since not all the presenters were mentioned in the reference section, they should list the name, title, organization, and city/state of the presenters. This information is available on the Open Forum Agenda. Ms. Roach will email the information to Dr. Mank the next day.

Ms. Starnes will send a written report of the following comments:

The References at the top of page 39 had a few lowercase "I"s that did not belong. This might be garbage data that got thrown in, a printing issue, or a messed up italics code. No problem existed in the electronic version. The same thing happened with question marks and URL listings.

On page 7, under the definition of intellectual disability, in the fourth paragraph, near the middle of the paragraph, it refers to a list of syndromes as cited above when the citation is actually below.

Ms. Roach will consult her style manual to see if a preposition should be capitalized in the title. She will report her findings to Mr. Mank.

Mr. Will Tienken thought they should add a brief statement in order for the reference to make sense. He will send a few sentences to Ms. Roach early the next morning.

Ms. Roach will get Judy O'Halloran's write-up of Casey O'Halloran's story which should be available shortly and pass it on to Dr. Mank.

Ms. Roach will send the names of the ex officio representatives to Dr. Mank for inclusion.

Everyone will have their information to Dr. Mank in a timely manner.

Mr. Tienken will email Ms. Roach the basics of how the letter to the new administration should be worded and set up.

Mr. Cole will setup a simple association using a tool like Linked In. He will work with the staff of disabilityinfo.gov to link the association to the disabilityinfo.gov website.

**PCPID Quarterly Meeting  
November 20, 2008**

**Award Ceremony to Honor the Late George Bouthilet, Ph.D.**

On November 20, 2009, Chairman Rhatigan opened the meeting by declaring that it was a special day for the Committee since they were assembled in order to honor the late George Bouthilet, Ph.D. The group was fortunate to include Mr. Dan Schneider, the Acting Assistant Secretary of the Administration for Children and Families. The successes that the Committee has and will have in this last report are due in great measures to Dan's commitment to Intellectual Disabilities. He and the PCPID Executive Director, Ms. Sally Atwater, made sure there were resources to get the job done. Chairman Rhatigan expressed his appreciation.

Mr. Schneider informed the group that he would be terminated in January 2009, but noted that it was a pleasure to work with everyone. He also commented on Dr. George Bouthilet, the award, and the awardees. Mr. Schneider observed that there are two ways to impact public policy: cultural institutions and valid research that shows public facts. He expressed the belief that the awards could not have gone to better people or organizations, as these have been involved with actual research and cultural institutions.

Mr. Harris Hollin talked about the life of Dr. George Bouthilet, former Research Director for at PCPID for 27 years. Mr. Hollin gave background information, talking specifically about activities with which Dr. Bouthilet was involved and discussing his character. Mr. Hollin then asked Ms. Mary Margaret Sharp-Pucci to introduce the honorees.

The first honoree was Allan Bergman, President and CEO of Anixter Center in Chicago. He has spent forty years in the field in different positions. In the ARC, the United Cerebral Palsy Association, and the Brain Injury Association of America, he held leadership positions. His public service record stretches from the local level to the national level. Mr. Bergman was an early pioneer in crafting family support and was instrumental in moving institutional services to community services. He has had his hand in much of the policy and legislation that guides these services as we know them today. As an ambassador and advocate, Mr. Bergman has made a real difference in the lives of people with intellectual disabilities.

Ms. Laverdia Roach introduced the second award, a special recognition of the Museum of Disability History. The museum is dedicated to advancing the understanding, acceptance, and the independence of people with disabilities using material that creates awareness and a platform for dialogue and discovery. This is the only museum dedicated to disabilities in the nation. Beyond the museum, their mission continued with traveling exhibits and a virtual museum online. These and many other

contributions by the Museum of Disability History make it worthy to be a recipient of Dr. George N. Bouthilet Award.

Each of the award recipients was invited to share remarks. Mr. Allan Bergman thanked the Committee, saying how honored he was to receive the award named for George Bouthilet, whose commitment and work quality Mr. Bergman had personally seen. He has been able to track the efforts of the Committee from almost the beginning, working closely with it between 1986 and 1998. Mr. Bergman believes in its mission, accomplishments and potential. He originally became involved with this work because of the poor treatment of people with intellectual disabilities which he observed early in his career. As that career has progressed, Mr. Bergman has been fortunate to work with many of the best and brightest. He then shared a success story in which he was able to help improve the lives of an individual with intellectual disabilities and the family of that individual. This sort of success helps him to continue working.

Dr. Francisco Vasquez accepted the award for the Museum of Disability History. He talked about the mission of the Museum. It presents the stories of people with developmental disabilities over time. Dr. James Boles originally created it because there was not a credible single source with information on the history of service to people with disabilities. In addition to the physical museum, a traveling exhibit and website make the materials available to a wider audience. Dr. Bouthilet took a very active interest in the museum before he passed away. Mr. Vasquez thanked the Committee for the award.

Chairman Rhatigan talked about Mr. Dan Schneider who gave crucial support to the Committee. He also acknowledged Mr. Neil Romano who helped to mold the group to its current state. The Chairman invited any comments from Mr. Romano. Mr. Romano said that he had come that morning to see friends and celebrate Dr. George Bouthilet. It was a pleasure and an honor for him to work with the Committee.

Chairman Rhatigan brought the meeting to a close with a few final words. The Committee started out as a new group with members unknown to one another. Mr. Rob Sweezy deserves credit for leadership which integrated new members into the Committee. The ex officio members were also extremely dedicated, following through on everything they committed to do. The Chairman extended an independent thank you to Ms. Linda Starnes, Mr. Ollie Cantos, Mr. Harris Hollin, and each member of the PCPID staff. He also reminded members of the committee that they will be receiving a copy of the proposed letter for the new administration. Members should send in review comments on that letter. Chairman Rhatigan expressed expectation that members would stay connected to one another.

A few individuals had closing remarks to add. Ms. Mary Ellen Zeppuhar conveyed her best wishes to the group and apologized that she could not attend the meeting in person. Dr. Sambhu Banik complimented the Committee for selecting Allan Bergman for an award. Mr. Eric Treat talked about the importance of taking into account

differences between the general public and people with intellectual disabilities. Ms. Sally Atwater thanked the Committee again, individually thanking Chairman Rhatigan and Chairman Emeritus Sweezy.

The meeting was adjourned by Chairman Rhatigan.