Minutes
June 25-27, 2008 Quarterly Meeting
President's Committee for People with Intellectual Disabilities

Participant List

Milton Aponte*
RoseAnn Ashby*
Sally Atwater
Richard Balkus*
Ricardo Barraza*
Jewel Bazilo-Bellgarde*
James M. Boles*
Christopher Button*
Olegario D. Cantos, VII*
David Carradini
Eric Lee Cole*
Berthy De La Rosa-Aponte*
Sharman Word Dennis*
William Edwards*
Margaret Giannini*
Carmela Vargas Gonzales*
Caffin Gordon*
Ron Gordon
Mark Gross*
Harris N. Hollin*
Stephen B. Hollingshead*
MJ Karimi
Charles Keckler
Patrick Leahy*
Patricia Mantoan
Mary Kay Mauren*
Naomi Miske
Brandon Mizroch
Casey Patrick O'Halloran*
Sue Picerno*
Stephanie Preshong Brown*
Harry A. Rainbolt*
Thomas J. Reilly*
Steven C. Rhatigan*
Laverdia T. Roach
Neil Romano*
Kodie Ruzicka Margaret
Schaeffer* MaryMargaret
Sharp-Pucci* Linda
Hampton Starnes* Dallas
"Rob" Sweezy* William
Tienken*
Eric Todd Treat*
Jim Troxell
Charles Weis*
Mary Ellen Zeppuhar*
Sheila Whittaker

* Committee Member

Proceedings of June 25, 2008

Executive Director Sally Atwater welcomed the Committee members and guests to the quarterly meeting of the President's Committee for People with Intellectual Disabilities. She asked the PCPID staff to introduce themselves to the Committee. Following the

staff introductions, Ms. Atwater introduced newly appointed Chairman Steven Rhatigan and presented him with the Presidential Order for his appointment. Ms. Atwater then turned the meeting over to Chairman Rhatigan.

Chairman Rhatigan welcomed the Committee members and expressed pride in working with such a group of proven advocates to combat the "soft bigotry of low expectations" that faced people with intellectual disabilities. Chairman Rhatigan stated his intent to work with each Committee member to provide a forum for the insight and experience each member brought to the table. He stressed the importance of openness, honesty, patience and respect. He also stressed the importance of placing the ultimate collective goal above individual desires in order to positively influence the increasingly challenging issues facing people with intellectual disabilities.

Chairman Rhatigan introduced Charles Keckler, Acting Deputy Assistant Secretary for Policy with the Administration for Children and Families (ACF), US Department of Health and Human Services.

Mr. Keckler began by expressing the Administration's pleasure to have PCPID within ACF. He provided a brief overview of the mission of ACF, including some background on the Administration's move from a traditional welfare agency to an agency that provides national leadership to providers of human services throughout the country so that they may better serve populations in need. He stressed that many of the challenges addressed by the Committee are at the state level and that the Committee must provide leadership for those on the front lines providing services.

Mr. Keckler spoke of the importance of the Federal Government being perceived as a government of citizens. He noted the importance of George Washington's voluntary resignation from the presidency to return to the life of a private citizen, and its signal to the world that America would be a single body of citizens, some of whom would go into public service for a time and then return to the citizenry.

Mr. Keckler noted three particular areas in which the Committee's work integrated with the mission of ACF: the New Freedom Initiative, emergency preparedness and prevention.

Following his remarks, Mr. Keckler officiated the swearing-in ceremony of the new members of the Committee.

The Committee then took a short recess for the members to sign their affidavits.

The Committee reconvened and approved the minutes of the April, 2008 quarterly meeting. The Committee members introduced themselves and spoke briefly of their interests and motivation for serving on the Committee.

The Committee then took a brief recess.

The Committee reconvened and the representatives from the various ex officio agencies introduced themselves and presented a brief description of the programs and services within their respective agencies that impact people with intellectual disabilities.

Chairman Rhatigan introduced Patricia Mantoan, Senior Attorney with the General Law Division of the Office of the General Counsel, US Department of Health and Human Services.

Ms. Mantoan explained to the Committee the Federal Advisory Committee Act (FACA), the statute governing Federal and Presidential advisory committees. She explained the purpose of FACA is to bring transparency to the advisory committee process and to allow public participation. She highlighted some of the statutory requirements of FACA and explained that the burden for compliance rested with the agency, not the Committee members. Ms. Mantoan explained that the Committee's annual report is filed with the Library of Congress to allow researchers access to past reports. Ms. Mantoan closed her presentation by stressing the importance of FACA compliance and then indicated her willingness to answer any questions.

In response to Committee members' questions, Ms. Mantoan explained that the scope of the Committee is provided in the Executive order and that the Committee's reports are ultimately to be made available to the public, but that there are clearance and vetting processes that may need to be completed before a report may be disseminated to the public.

Chairman Rhatigan thanked Ms. Mantoan for her presentation and introduced Naomi Miske, Associate Counsel for Ethics Education, Office of the General Counsel, US Department of Health and Human Services.

Ms. Miske began by defining a special government employee (SGE) and noting that SGEs have relaxed ethics rules when compared to full time Federal employees. She encouraged the members to take a look at the ethics rules and regulations and noted that the most important thing to come away with is the name of the ethics official responsible for the Committee—Curtis Coy.

Ms. Miske indicated that the central ethics rule that the Committee members should concern themselves with is that they are prohibited from participating in a matter that would have a direct and predictable effect on their own financial interests. She noted that these rules are codified in a criminal statute and that violation of the rules could come with fines and possibly prison terms. She also noted that the interests of a spouse, minor child, employer, general business partner or affiliated organization may also have interests which can be imputed to the members. Ms. Miske advised the Committee members to immediately contact their ethics official if they feel that they may have a possible conflict.

Ms. Miske discussed some of the scenarios in which a conflict may arise and related some examples. She described the requirement and process for filing the OGE form 450 (financial disclosure form), noting that Committee members are required to fill them out

annually. Ms. Miske related the various options for working around identified conflicts such as filing a waiver.

Upon Ms. Miske's discussion of the ethics guidelines relating to Committee member activities during and after their terms of service expire, several Committee members raised questions regarding the lifetime ban on certain activities, and the definition of "personally and substantially" as it relates to government ethics for SGEs. The Committee members asked for additional clarification on several issues and Ms. Miske suggested that the Committee members notify her office with any questions about particular activities that may potentially be in conflict with the ethics statutes and guidelines.

Ms. Miske concluded her remarks and Chairman Rhatigan thanked her for her presentation.

Chairman Rhatigan introduced former chairman Rob Sweezy to give the Committee a historical view of the Committee's activities and his reflections on the work of the previous Committee.

Mr. Sweezy acknowledged the work begun by the previous Committee and expressed the hope that the new Committee might pick up and continue to move forward with some of their work. He reiterated the charge to the Committee from then Assistant Secretary Wade Horn to be bold. He noted that not only does the Committee have the opportunity to share its collective knowledge with policy makers, but that each Committee member can take back to their communities what they learn from each other. He urged the members to take advantage of the ex officio members serving on the Committee.

Mr. Sweezy concluded his remarks and Chairman Rhatigan thanked him for his leadership in the prior work of the Committee.

The meeting then recessed for lunch.

The meeting reconvened with two additional ex officio agency presentations. Chairman Rhatigan noted that in regards to the presentation on ethics given earlier that morning, Ms. Miske, agreed to put together a new handout for the Committee members that would be more specific to the ethics regulations and guidelines as they applied to SGE's. He then introduced the film, *Life in the Shadows*.

At the conclusion of the film, Dr. Giannini provided the Committee with some additional background information regarding the University Centers of Excellence discussed in the film, and Ms. Roach provided additional background information regarding the history of the Blue Ribbon Panel discussed in the film.

Chairman Rhatigan began a discussion on the 2009 Annual Report to the President by noting that for those who had particular areas of interest that may not be included as

part of the 2009 report, the opportunity may be available to partner with one or more of the ex officio agencies to host a roundtable on the issue.

Chairman Rhatigan urged the Committee to be cognizant of the limited number of PCPID staff and urged the Committee to be sensitive to that fact as they developed their approach for the 2009 report. He discussed his desire to recruit two vice-chairs and named Ollie Cantos and Linda Starnes to serve in that capacity.

Chairman Rhatigan turned the time over to Ms. Atwater to discuss the PCPID Procedures Manual.

Ms. Atwater began by explaining that the Executive order and charter of the Committee provide the Committee's marching orders. She particularly noted that the most recent Executive order and charter reflected the language of the New Freedom Initiative, and that in 2003 President Bush changed the name of the Committee to reflect people-first language. Ms. Atwater explained some of the housekeeping logistics of the Committee and that the Committee membership was pulled, in part, from several Federal agencies and that each had an equal vote on the Committee.

Ms. Atwater reminded the Committee that they—and she—serve at the pleasure of the President. She noted that the status of the current Committee may or may not change during the upcoming transition to a new Administration.

Ms. Atwater reviewed the procedure for communicating with the PCPID chair, executive director and staff. She explained that she is the Designated Federal Official (DFO) and that her role as such is defined by FACA.

Ms. Atwater discussed the Committee's responsibility to provide an annual report to the President. She addressed the Committee's previous questions regarding publication and public dissemination of the report and explained that PCPID has a constituency of one—the President. She noted the process outlined in the Procedures Manual for identifying national issues for consideration in the report and the importance of being creative and working together. She also explained the process for voting on the final draft of the report.

Ms. Atwater affirmed Chairman Rhatigan's admonition to be cognizant of the number of staff available to the Committee and noted that the ex officio members also served as a source of information and guidance in the preparation of the report.

Ms. Atwater related the process for holding quarterly and subcommittee meetings and the different options for putting together a report. She mentioned the possibility of partnering with other agencies to fund roundtables or conferences.

Ms. Atwater then took questions from the Committee members and addressed the clearance process and the status of the previous years' reports.

In response to a question, Ms. Roach explained that prior to 2000, all reports to the President were delivered to the White House in a published format, but that since that time, PCPID has been advised that it may not publish any report without express permission from the White House. The Committee discussed the issue further and Chairman Rhatigan noted that this had been an ongoing conversation for several meetings. He acknowledged the frustration of not printing the reports, but stated his belief that just the dialogue taking place at Committee member meetings has an impact on people with intellectual disabilities because of the movement it generates.

Several members expressed their belief that advocacy organizations, private citizens and Committee members should contact the White House and urge then to release the reports for publication—including an official letter from PCPID. A discussion followed of the appropriateness of quasi-dissemination through the Freedom of Information Act (FOIA) provision that allows for the public to request a copy of the draft.

Mr. Hollingshead noted that one of the action items from the last meeting included writing two letters to the White House; one to request that the White House release the previous reports for publication, and one to request that the Committee receive a line-item in the budget.

Mr. Boles expressed his concern with the short timeline for the last report and suggested that the Committee allow for more time to complete the 2009 report. Mr. Weis recommended that the Committee not rush the report based on the upcoming change in Administration. Mr. Balkus noted that the ex officio agencies needed an appropriate amount of time to send the report through the clearance process.

Chairman Rhatigan turned the conversation to potential topics for the 2009 report and Harris Hollin implored the Committee to continue supporting the research applications subcommittee which could then contribute the research aspect to any topic chosen as the focus of the 2009 report.

There was a discussion of the role of ex officio members in choosing the topic for the annual report and their general role on the Committee.

The Committee discussed potential topics for the report including:

- Employment for people with intellectual disabilities—addressing the supports and barriers including transportation, benefits, institutional barriers, housing, education and transition from education to employment;
- Replacing the term mental retardation with intellectual disabilities in all Federal legislation and statutes;
- Research;
- Inclusion and the faith community (Ms. Starnes volunteered to draft an additional report on the topic); and
- Public awareness.

Mr. Hollingshead noted the importance of developing a well-defined structure for the report with a very precise list of action items in order to ensure that the report does not become too big for the Committee to adequately address in the appointed time.

The Committee then debated the use of the terms work and employment with some Committee members preferring the more broad term of work—encompassing all work activities, paid or unpaid—and others preferring the more narrow term of employment—encompassing only paid work. Suggestions were made for potential titles that would encompass all of the topics discussed during the session and a debate of those suggested titles ensued.

Several members noted that the topic of employment had not yet been officially voted as the topic of the 2009 report, but Chairman Rhatigan did note that employment/work had received the most votes on the preference sheets distributed via email and at the meeting. Mr. Cole and Mr. Weis suggested that employment/work could be one topic under a larger umbrella of topics, but that it should not be considered the only topic. Mr. Weis further noted that people should be allowed to participate where they feel they would be the most useful.

Mr. Rhatigan announced that the vans for transportation back to the hotel would be arriving shortly and that the Committee could pick up the discussion the following day. The Committee then discussed logistics for the following morning's swearing-in ceremony and the meeting recessed.

Proceedings of June 26, 2008
Ms. Atwater called the meeting to order and Ms. Roach gave an overview of the ex officio clearance process for the annual report.

Chairman Rhatigan pointed out the handouts given to the Committee members—the first a document written by Mr. Cantos synthesizing the discussion from the previous day's session, and the other an excerpt of the PCPID annual report from 1983 entitled *The Mentally Retarded Worker*. Chairman Rhatigan mentioned that the 1983 report may serve as a useful template for the 2009 report. He also reiterated the previous day's discussion about using a "Christmas tree and ornaments" model for assembling the pieces of the report.

Mr. Hollin noted that the Research Application subcommittee would participate by including a research component, as applicable, to topics chosen by the Committee.

The Committee briefly discussed the New Freedom Initiative Progress Report and the lack of content specific to people with intellectual disabilities. They discussed the potential title for the report and Chairman Rhatigan encouraged the Committee to adopt a title beginning with the phrase, "heightening public awareness of…"

Mr. Cantos gave a brief explanation of the synthesized issues previously handed out to the Committee members. He suggested that the members review the document, recommend changes, and then divide into subcommittees to begin work on specific assignments.

The Committee discussed the possible inclusion in the report of a section on employment for people with fetal alcohol syndrome (FAS) and it was suggested that the issue be addressed in a separate forum dedicated solely to the topic of FAS/ID.

The Committee discussed using past reports addressing employment to highlight the progress made and the steps still to be taken to increase employment opportunities for people with intellectual disabilities. They also discussed the need to put the previous reports on the Committee's website and Ms. Ruzicka explained that the PCPID staff was currently in the process of making that possible.

The Committee discussed possible formats for the report and how to organize the subtopics under employment. They discussed whether or not the report would be a tactical report or a strategic report, and the need to address the inspirational importance of people with intellectual disabilities in the workforce. The Committee again discussed potential titles for the report including inclusion of the term "innovative approaches," and also further discussed whether the report should primarily focus on paid employment, or the broader concept of work.

Chairman Rhatigan—in response to the clarification that the topic/framework had not yet been officially adopted—called for a motion on the topic of the report and the Committee voted unanimously to support the topic of employment.

The Committee discussed the need to focus on innovative approaches to employment for people with intellectual disabilities. They also discussed the importance of using personal stories and examples to highlight the successes of people with intellectual disabilities in the work force.

The Committee discussed the need for public awareness and Mr. Weis volunteered to serve as an asset to the Committee for getting the message out when necessary.

Several Committee members noted the increasing levels of volunteerism on college campuses and discussed the potential of tapping into that resource. The Committee turned again to discussing the differences and preferred language for discussing work versus paid employment and determined to separate volunteerism into two categories: people that volunteer with people with intellectual disabilities, and people with intellectual disabilities that volunteer.

Several members suggested additional ornaments for the framework of the report, including: transportation, employment for people with fetal alcohol syndrome, stepping stones to employment, work incentives, self-employment, asset development and benefits.

Mr. Tienken suggested that for its next meeting the Committee should (as suggested in previous meetings by Neil Romano) partner with the Office on Disability Employment Policy at the US Department of Labor and bring in employers currently hiring people with intellectual disabilities.

The Committee discussed the importance of recognizing that people with intellectual disabilities represent a diverse group of talents and levels of ability. They also discussed the importance of addressing the obstacles to employment in relation to small, medium and large size companies as well as the available tax incentives.

Ms. Ruzicka stressed the importance of developing concrete recommendations that are specifically connected to the text of the report. Mr. Aponte added that the first step in accomplishing the goals of the report is to convince the President to use the power of the Executive to implement the Committee's recommendations.

The Committee then took a brief recess.

Chairman Rhatigan initiated the next portion of the meeting with a discussion of several pieces of pending legislation relating to asset development for people with disabilities.

The Committee then began a discussion of the suggested subtopics (ornaments) for the report and Mr. Weis noted that the public awareness piece should be broken down into two sections: the big picture and the specifics. Ms. Roach read aloud the current suggested title of the report, *Heightening Public Awareness of Innovative Approaches for Enhancing Work Incentives, Opportunities and Economic Self-Sufficiency*, and the ten subtopics identified by the Committee throughout the meeting: public awareness, innovative approaches including success stories and testimonials, volunteerism,

education, housing, transportation, FAS, benefits—including work incentives and employer benefits and incentives—self employment and asset development. The Committee discussed combining benefits, asset development and incentives into one group. They discussed again the possibility of working with Neil Romano and ODEP. They discussed the possibility of using Mr. Weis' access to the media (particularly during football season) to communicate messages to the public regarding people with intellectual disabilities, and networking through the nonprofit and advocacy community to disseminate Committee information.

The Committee considered whether housing and transportation should be treated together or separately in the report. They debated the need/appropriateness of including certain topics in the report (employment for people with FAS/ID, housing) and Chairman Rhatigan noted that the list of topics currently under discussion reflected only the interests of Committee members as expressed during the meeting, but did not necessarily mean that all of the issues would be included in the final report. He noted that as the Committee moved forward in its work, some issues may need to be excluded from the final report. He also noted that members whose particular interests do not make it into the final report may wish to consider putting together a separate report for the Committee's consideration. Mr. Aponte noted that the Executive order and charter provided parameters for which topics the Committee should focus its attention on.

Ms. Bazilio-Bellgarde suggested that the success stories run throughout the document and Chairman Rhatigan agreed it was a good approach to integrating the success stories into the larger document.

The Committee discussed the schedule for the following day and Mr. Aponte suggested that the Committee consider how it might reenergize the ex officio representatives (at the secretary level) to become active participants in the Committee.

The Committee then recessed.

Proceedings of June 27, 2008

Chairman Rhatigan welcomed the Committee members to the final day of the PCPID quarterly meeting (held at the Department of Labor) and introduced speaker Neil Romano, Assistant Secretary, US Department of Labor, Office of Disability Employment Policy (ODEP).

Mr. Romano began by expressing his pleasure in addressing the Committee and indicated his commitment to partnering with the Committee to provide the necessary resources to continue its work. He stressed the impact that his work with the Committee has had on his life.

Mr. Romano introduced the shortened version of his film, *America's Strength*, which was then viewed by the Committee. Mr. Romano stressed that the stories highlighted in the film did not represent a magic formula and that many people with intellectual disabilities can have and maintain a job.

Mr. Romano addressed the timeline for the release of the full version of the film and promised a copy to each member of the Committee. Chairman Rhatigan asked Mr. Romano how he would like to proceed with his offer of financial support for the Committee's activities and Mr. Romano indicated that requests could be made through Chairman Rhatigan or Ms. Atwater. He also indicated his desire to continue to hear from the members of the Committee. Ms. Atwater informed the Committee that in order for the two agencies to work together a formal document must be developed in accordance with Federal guidelines.

Chairman Rhatigan thanked Mr. Romano for his remarks and his hospitality in hosting the Committee's meeting at ODEP.

Chairman Rhatigan introduced Jim Troxell, Network Developer, Employment Support Institute, Virginia Commonwealth University.

Mr. Troxell began with a brief description of the Employment Support Institute. He noted that many people do not understand the programs and policies relating to benefits and incentive programs and that the Employment Support Institute's focus is on developing technology applications to help explain those policies. He noted that there is currently a focus on informed choice and that the goal of the Institute is to help people make decisions and be informed about the choices available to them.

Mr. Troxell discussed some of the challenges when trying to navigate the benefits and incentives system and noted that many people feel overwhelmed when trying to navigate the system, or find people who can provide specific, knowledgeable advice. He discussed the phenomenon of learned helplessness due to assistance and systems barriers and noted that complexities exist in the form of cross benefit interactions that many people are not aware of, but that potentially affect their benefits across various programs.

Mr. Troxell stated that many incentive programs provide powerful opportunities to people wishing to take steps toward greater income opportunities and independence, but that people don't understand the programs or how to apply for them. He noted that the combination of the above factors leaves people discouraged and fearful of making changes to the status quo resulting in unemployment and underemployment of people with disabilities.

Mr. Troxell stated that the Institute has focused its efforts on creating tools to provide decision support systems that show people that they can take actions confidently and take a risk that is, in fact, an opportunity.

Mr. Troxell discussed the components and functions of the decision support system and stressed that it is a vehicle for helping people understand their current situation by providing specific information and resolving the ambiguities of benefits and incentives policies.

Mr. Troxell then conducted a demonstration of the WorkWORLD software, highlighting its comprehensive help and information system. He noted that the system delivers results for major Federal benefits programs, and is customized to include several state systems as well. He further noted that the system is written in clear, understandable language and that the program is available on the web, free of charge.

Mr. Troxell answered questions from the Committee members. Chairman Rhatigan stated that his motivation for inviting Mr. Troxell to present to the Committee was so that the program can be used by the Committee members and shared with individuals and advocates in their respective states.

Mr. Troxell concluded his demonstration and Chairman Rhatigan thanked him for his presentation.

Mr. Hollin recommended that the Committee establish the George N. Bouthilet Award to be presented annually to the citizen who has, through his or her company, done outstanding work to employ people with disabilities. He recommended that the nominations be made by the citizen members of the Committee, and the selection made by the full Committee. The Committee voted approval of the recommendation.

Mr. Edwards noted that Mr. Bouthilet was also a pioneer in the field for people with disabilities in the criminal justice system, and recommended that the Committee establish an award for someone in the criminal justice system working with children with disabilities. He noted that the Committee could work in tandem with the Justice Department. The Committee voted approval of the recommendation.

Chairman Rhatigan and Ms. Atwater presented to the Committee the dates of September 8-11 for the next quarterly meeting and Ms. Roach informed the Committee that they would be receiving information on employment that had been gathered by the previous Committee.

Ms. Dennis stated that at previous quarterly meetings, invited speakers have not always been people-first in their language and have used the inappropriate term, mental retardation (outside of an historical context). Ms. Dennis recommended that the PCPID staff send out a letter to future speakers outlining the mission and focus of PCPID and request that they be people-first in their language.

Chairman Rhatigan stated that members of the Committee will be getting a list and ranking of the ornaments previously developed at the quarterly meeting and that subgroups would be formed. He again outlined the protocol for communication with the PCPID staff and noted that he is always available via phone or email. He also asked that the Committee members refrain from communicating with Mr. Romano on issues relating to his offer of financial assistance to the Committee until the PCPID staff prepares the necessary memorandum of understanding.

The Committee then adjourned.