



Minutes
President's Committee for People with Intellectual Disabilities
Quarterly Committee Meeting
September 13-14, 2004

Attendees:

PCPID Civilian Members:

Vijaya L. Appareddy, M.D.
Nancy C. Blanchard
James T. Brett
Mary C. Bruene
Claudia L. Coleman
Olivia R. Colvin
Zoraida F. Fonalledas
Kathy Hargett
Kenneth E. Lohff
Brenda A. Leath
Edward R. Mambruno
Alvaro A. Marin
Kim Porter-Hoppe
Karen L. Staley
Windy Smith
Gene C. Stallings
Madeleine C. Will

PCPID Ex-Officio Members:

Milton Aponte (NCD)
Representing Lex Friedman
John P. Benison (DoT)
Representing Norman Y. Mineta
ReJane "Johnnie" Burton (DoI)
Representing Gale A. Norton
Jeremy L. Katz
Representing Donald L. Evans
Claudia Gordon (DHS)
Representing Tom Ridge
Mark Gross (DoJ)
Representing John Ashcroft
Joan Mele-McCarthy (ED)
Representing Roderick R. Paige
Marcia Martin (HUD)
Representing Alphonso Jackson
Mildred Rivera (EEOC)
Representing Cari Dominguez
Glenn Sklar (SSA)
Representing Jo Anne Barnhart
Nancy Skaggs (DoL)
Representing Elaine L. Chao
Daniel W. Sutherland (DHS)
Representing Tom Ridge
LaMonica Shelton (CNCS)
Representing David Eisner

Guest Speakers:

Claude Allen
Deputy Secretary
U.S. Department of Health and Human Services
John J. McGee, Ph.D.
Executive Director
Gentle Teaching International, Inc.
and Joint Compliance Coordinator,
U.S. v. Commonwealth of Puerto Rico

Jennifer L. Dorn
Administrator
Federal Transportation Authority
U.S. Department of Transportation

Daniel Sutherland
Director, Office of Civil Rights and
Civil Liberties
U.S. Department of Homeland Security

Tracy Justesen
Associate Director
Office on Domestic Policy Council
The White House

Neil Romano
The Romano Group

Patricia Mantoan
Attorney
General Law Division
Office of the General Counsel
U.S. Department of Health
And Human Services

John Condray
Attorney Advisor/Ethics Counsel
Office of General Counsel
Ethics Division
U.S. Department of Health
and Human Services

Chris Downing
Director
Office of Public Affairs
Administration for Children and
Families

Joanne Wilson
Commissioner
Rehabilitation Services Administration
Office of Special Education and
Rehabilitative Services (OSERS)
United States Department of
Education

PCPID Staff:

Sally Atwater
Executive Director

George Bouthilet, Ph.D.
Research Director

Laverdia Roach
Special Assistant to the Executive Director

Jarnice Roach
Administrative Assistant

Lena Stone
Program Specialist

Sheila Whittaker
Budget Officer

Guests

Alecia Cole (SLA)
Maria Archambault (National Fragile X Foundation)
Marge Brown (Gentle Teaching International, Inc.)
Laura Canfield (HHS/OGC)
Ranee Chafkin (DoL)
Doreen Croser (AAMR)
Richard Ferrano (DoJ)
Susan Goodman (NDSS)
Andrea Lack (NDSS)
Susan Leitson (SLA)
George Jesien (AUCD)
Margaret A. Nygren (AUCD)
Jerry Provencal (MORC)
Kenneth Ringlein (EEOC)
Mildred Rivera (EEOC)
Rick Rader, M.D. (Exceptional Parent Magazine)

Monday, September 13, 2004

The President's Committee for People with Intellectual Disabilities (PCPID) convened at 8:30 a.m. on Monday, September 13, 2004, in Washington, DC. The purpose of the meeting was to swear in re-nominated members, discuss issues relating to dissemination of the 2004 Annual Report to the President and Companion Booklet and to discuss 2005-2006 focus areas for the Committee.

Opening Remarks

Chairperson Madeleine C. Will welcomed PCPID members, speakers and guests. She asked that members review the minutes of the January 29-30, 2004 quarterly meeting which had been sent to them prior to the meeting. Karen Staley made a motion for approval of the minutes. The motion was seconded and the minutes were approved as written.

Mrs. Will welcomed new ex officio representatives: LaMonica Shelton, Policy Analyst, Corporation for National and Community Service; Jeremy Katz, Deputy Direct of Policy for Secretary Evans, Department of Commerce; Susan Goodman, Consultant to Deputy Commissioner to Martin Gerry, Social Security Administration; Susan Parker, Policy Director, Office of Disability Employment Policy, representing Dr. Roy Grizzard, Assistant Secretary, Office of Disability Employment Policy, Department of Labor.

Implementation of Olmstead Decision in Puerto Rico

Chairperson Will introduced John J. McGee, Ph.D., Executive Director, Gentle Teaching International, Inc. and Joint Compliance Coordinator, *U.S. v. Commonwealth of Puerto Rico*.

Dr. McGee thanked the Committee for asking him to speak. He described the mission and activities of Gentle Teaching International, Inc., which is to deepen and spread a spirit of gentleness toward people with intellectual disabilities throughout the world. In August 2004, the company held its 5th International Conference on Gentle Teaching in Denmark; nineteen nations were represented.

He provided an overview of the success that Puerto Rico has had in bringing people with intellectual disabilities out of institutions into loving group homes. He showed a video presentation of two of the homes in Puerto Rico which depicted the successes of implementation of the *Olmstead Decision*.

Legal action was brought against Puerto Rico in 1999. Puerto's response was to create a system based on its cultural values. In 2000-2001, the Commonwealth of Puerto Rico developed a plan. All but one of their institutions for children with autism have been closed. That one will be closed this year.

Dr. McGee showed another video on conditions that existed and some of the work Gentle Teaching has done just out of Mexico City when they first started. His purpose in showing the video was to give the Committee members and audience hope and to ask for help in changing the lives of these people.

Presenter/PCPID Dialogue

There was active dialogue between many members and Dr. McGee, including:

Ms. Fonalledas inquired about staffing and funding for Dr. McGee's organization. Dr. McGee said that initially, he was the only professional. They currently have five 35 homes with the same staff. If there are bad homes, they are cut off.

Karen Staley asked if Inclusion International is doing anything to help in the Americas. Dr. McGee responded that there are a lot of international organizations involved in helping the Americas, but they don't get as involved as they should with the poorest of the poor.

Nancy Blanchard mentioned that she has been very active in the foster care treatment program for over 25 years. Over time a great fear of physical and sexual abuse accusations has developed among foster parents. She wanted to know how this issue could be addressed.

Dr. McGee suggested vigilance in the fight against the use of physical management in any group home while at the same time exerting leadership. He mentioned a policy that he wrote for the Canadian Association of Community Living (CACL) which is considering a national policy on nonviolence in all of their programs and services.

Chairperson Will thanked Dr. McGee for his presentation.

President's Executive Order on Human Service Transportation Coordination

The Chair introduced the next speaker, Jennifer L. Dorn, Administrator, Federal Transportation Authority, U.S. Department of Transportation.

Mrs. Dorn expressed her appreciation for the opportunity to discuss the President's Executive Order on Human Service Transportation Coordination. She complimented Transportation's interagency work in ensuring that individuals across all walks of life, including those with intellectual disabilities, have access to these key human services.

Mrs. Dorn discussed the multiplicity of federal programs: 62 in total, across the spectrum of human services, education, labor and transportation that provide eligibility for transportation for all of the various stakeholders in human service programs.

One of the key issues of the Executive Order is to coordinate transportation services within a community and programs within a state and across the federal government to provide easier access to transportation for consumers and people who need it. A panel of about 26 experts, made up of service providers, clients from all human service perspectives, and transportation agencies across the state, federal and local arena, recently convened to focus on the fundamental building blocks and challenges to solve this problem. Forty seven states were represented. Mrs. Dorn provided a handout *The Framework for Action* to the members, which is a community assessment tool that allows stakeholder and provider groups in local communities and states to figure out where they are on desired outcomes of a fully coordinated transportation system. Statutory and regulatory duplications and barriers to human service transportation coordination need to be identified by the interagency group.

Presenter/PCPID Dialogue

There was a dialogue with some members. Mark Gross expressed his belief that transportation should be a local program and wanted to know exactly what services the federal government provides. He asked if for some examples of federal programs that are not in the Transportation Department.

Mrs. Dorn stated that the federal programs provide money, with strings, and have become a complex web for people with disabilities. Some of the money is distributed through governors and then to local service providers. A minority of it goes directly to communities. Of the 62 federal programs, only one or two have the name "Transportation" in them. The others are everything from the Office of Disability Employment Policy to the Centers for Independent Living, Medicare and Medicaid Services, Health Resources and Services, and World Transit Operators. It goes on and on. There are 33 programs within the Department of Health and Human Services; some provide vouchers.

Mrs. Dorn expressed her appreciation to Madeleine Will and Sally Atwater and the Committee members for the work they have done and felt that together we can make some incredible progress.

President's Executive Order for Establishing the Interagency Coordinating Council on Emergency Preparedness

Chairperson Will introduced the Daniel Sutherland, Office for Civil Rights and Civil Liberties, U.S. Department of Homeland Security (DHS).

Mr. Sutherland expressed his thanks for being invited to speak to the Committee again. He introduced, Claudia Gordon, an attorney in his office, who would assist him in providing an update to the Committee on the Interagency Coordinating Council on Emergency Preparedness Initiative that the President created on July 22, 2004. He thanked Tracy Justesen who orchestrated the Executive Order at the White House.

The mission of his office at DHS is to provide legal and policy advice on civil rights and civil liberties issues. Both Mr. Sutherland and Ms. Gordon have expertise in disability law. They also deal with technology and privacy issues, law enforcement issues, information sharing and information gathering. DHS is focusing on four areas within its department: (1) Making DHS a model department, (2) Employment of people with disabilities, (3) Accessibility of information technology under Section 508 (4) and Screening at airports.

Ms. Gordon explained the purpose of the Interagency Coordinating Council on Emergency Preparedness Initiative. It is to set up a model on emergency preparedness for people with disabilities to ensure that the federal government appropriately supports the safety and security of individuals with disabilities in both man made and natural disasters. It branches out to provide models that can be replicated at the state, local and tribal levels. Different federal agencies and departments have come together to ensure that the work of the Council is coordinated in order to eliminate duplication, ensure that there were experts leading the work and to fill in the gaps in areas that had not been addressed. The goal is to coordinate, identify and stimulate.

Some of the steps DHS has taken are:

- Supporting a major conference on September 22, 2004, in collaboration with the National Organization Disability. Secretary Ridge will be the keynote speaker.
- Grant making which will allow DHS to tap into the expertise of disability organization and communities and develop projects that will resolve some of the emergency preparation issues and concerns.
- Providing technical assistance. FEMA is updating some of its materials that provide technical assistance to the ACCESS Board. Workshops to focus on emergency preparedness are planned in October.
- Updating the website for ready.gov to provide more information regarding emergency preparedness for people with disabilities.
- Develop partnerships with the private sector and disability organizations.
- Form subcommittees through the Citizen Corps Council.

Mr. Sutherland invited the Committee to let him know how it can participate and help them in tackling the issue of preparing people with disabilities for emergency situations. He felt that PCPID's proposed subcommittee on homeland security would be a perfect way for it to interact. He asked the Committee to focus on emergency preparedness for people with intellectual disabilities. Mr. Sutherland opened the floor for questions.

Presenter/PCPID Dialogue

Mark Gross asked what DHS had done regarding the needs of people with intellectual disabilities. Mr. Sutherland replied that emergency preparedness is now what DHS has done because it is a federal agency and the problems have to be worked out on a local basis. Their primary role is to stimulate state and local government to integrate people with disabilities into the planning. In addition, FEMA has put up materials on a variety of emergency preparedness issues.

Mrs. Will asked if it would be helpful if the Committee could identify some of the complexities of how people with intellectual disabilities would react and ways in which they would need to assist them. Mr. Sutherland welcomed that suggestion.

Susan Goodman mentioned the problem of screening of people with disabilities at the airports and asked if that was one of the areas they were looking into. Mr. Sutherland stated that the Transportation Security Administration runs that program. He suggested that the Committee look at TSA's website, <http://www.tsa.gov/public>, which offers information for people with all disabilities, not just physical. He offered to bring in the head of the program to brief the Committee at another meeting.

Brenda Leath commented that in the past her private organization had done work around preparedness directed specifically at children. There is still a tremendous need for planning and integration, even at the local level.

Working Lunch

Progress Report on the President's New Freedom Initiative

Mrs. Will introduced Troy Justesen, Associate, Director, Office on Domestic Policy Council, the White House. During lunch and off the record, Mr. Justesen provided an update on the status of the New Freedom Initiative for people with disabilities.

Office of General Counsel Briefing on the Federal Advisory Committee Act (FACA)

Mrs. Will two individuals from the Office of General Counsel: Demetrious Kouzoukas, Special Assistant to the General Counsel, Office of the General Counsel, U.S. Department of Health and Human Services, and Patrician Mantoan, Senior Attorney. Mr. Kouzoukas is responsible for issues across HHS that are handled by the Office of General Council's Ethics and General Law Division. Ms. Mantoan is the level expert on the Federal Advisory Committee Act (FACA), the Freedom of Information Act and the Privacy Act.

Mr. Kouzoukas thanked Mrs. Will and the Committee for the opportunity to speak before them. He stated that Ms. Mantoan is the person that the Office of General Counsel calls upon regarding FACA and other issues, and so he asked her to make the presentation.

For purposes of the Committee, Ms. Mantoan said that the FACA statute is a very important one that affects the members' roles and duties. She provided background information on FACA, which was passed in the mid-seventies. The main purpose of FACA was to make federal advisory committees open to the public. A key cornerstone of FACA is openness.

The PCPID was established by a Presidential Executive Order that was created to provide advice to the President and the Secretary of the Department of Health and Human Services. The role of an advisory committee is simply to give advice. What that means is that the Committee's role is to give the President and the Department of Health and Human Services recommendations and suggestions on what can be done in the intellectual disability area. It is a simple point, but one worth stressing. Work by the Committee is the advisory nature of the committee. The requirement is in the FACA. Ms. Mantoan provided a handout to the Committee members with the specific section of the statute highlighted. The only time that the role of the Committee could change is by statute or Presidential directive.

Ms. Mantoan relayed that she had conducted some research on the PCPID and found that "there is no a Presidential directive that gives this committee non-advisory functions."

After the Committee makes a public report that contains recommendations and advice, that report first goes to the Secretary of Health and Human Service. Next it goes to the President. A statute in FACA requires that the President, within one year of receiving the report, make a report of his own to Congress to let them know what actions the government will be taking with respect to recommendations contained in the report. It would also explain any inaction and the reasons for that inaction; for example, a decision not to implement certain recommendations of the report because of legislation, authority, appropriations, judicial decision, state resources, and/or other reasons.

Presenter/PCPID Dialogue

A member of the audience asked what happens with the recommendations within that one year timeframe.

Ms. Mantoan explained that the Committee itself does not take action to implement the recommendations that it made. She again emphasized that the role of the Committee is solely to give advice. It is the function of the President and government officials to implement those recommendations or to issue policy based upon the recommendations.

Annette Talis asked if it was possible for an ex officio member of the Committee, who is also the head of a government agency that implements policy, to implement the recommendations without waiting for the President to submit his report to Congress. As an example, some of recommendations of the Subcommittee on Education are related to the *No Child Left Behind* act and are in sync with what the Department of Education is doing. Could not the Committee members work with the Attorney General as they are working on some of these initiatives?

Mark Gross, ex officio representative of the Department of Justice, responded to the question. He said that “obviously an agency that has authority to do something has the authority to do that regardless of what the Committee says. It either has authority or doesn’t have authority.” He personally felt that there are very few things set out in the report that are within the authority of any single agency.

He continued that “if an agency chooses, it can see the report and say ‘that sounds great to us, let’s do it.’” However, Mr. Gross felt that the report doesn’t contemplate any single agency acting as a result of the report, although the report talks about interagency cooperation.

Ms. Mantoan expanded upon Mr. Gross’ comment. “Because there are areas of the Committee that involve several federal agencies’ interests, it is probably the best reason why we have a presidential advisory committee to go to the President, who will then implement any recommendations and farm them out to individual federal agencies.”

She emphasized the following points:

- While the work of the Committee may sound like preparatory work, it has issued recommendations and is waiting to hear from the President. If the committee starts implementing recommendations and taking action based on those recommendations, it would be crossing the line into non advisory recommendations.
- Ex Officio members that are on the Committee are also federal government officials and they have their own responsibilities in their agency. Because there are ex officio members on this Committee doesn’t make all the other members of the Committee officers of a particular agency.
- If members speak about non-confidential Committee issues that could be raised with the public, they should provide a statement that their comments are their own personal opinion, unless they have been asked to speak for the Committee.

Kim Porter-Hoppe asked if she would be allowed to speak about the recommendations as an individual, rather than a Committee member. For example, as a school board member, if she should make a speech on behalf of her school board and happened to mention that she is a PCPID Committee member and talked about some of the wonderful things they have done, wouldn’t she be within her purview as a citizen of the United States?

Ms. Mantoan concurred that, under the First Amendment, she would be allowed to do that but that she must state this she is not speaking for the Committee, but rather as an individual.

Mrs. Leath also wanted to know what happens to the Committee Recommendations if there is a change in Administrations during the November 2004 election.

Ms. Mantoan explained that, based upon her prior experience, the workload from the previous administration carries over the next administration, as a requirement of the Federal Advisory Committee Act.

Mrs. Will asked what the Committee members are allowed to discuss, both as members of the Committee and as individuals, at the outside level (state and local levels) with respect to the report while they await a response from the President.

Ms. Mantoan explained that if members of the Committee start talking about the recommendations, they will be giving the impression that they are speaking for the Committee, and would be going beyond the functions of the Committee. They may talk to people about the recommendations as a private U.S. citizen, but they must state that they are speaking about it in their own personal capacity; that is up to the President to decide what to do with the recommendations.

Ed Mambruno stated that even if a member speaks of the recommendations, he/she would be putting themselves in a position where it could be misconstrued. So, wouldn't it be better to just not say anything? Ms. Mantoan remarked that she cannot legally gag anyone from talking to the public or to the press but she cautioned, as a matter of discretion, to at least let the people know that you are speaking in your own personal capacity.

Nancy Blanchard asked if the same restrictions apply to the booklet. Ms. Mantoan explained that the dissemination of booklet is a policy issue and that it has to go through clearance internally

before it can be disseminated to the public or even discussed in a public venue. It is outside the Office of the General Counsel and the Office on Government Ethics.

A member asked if the Chair has a different role in representing the Committee than the members do.

Ms. Mantoan said that, yes, the chair does have a slightly different role. She provided a handout which explains that the chair advises and counsels the Committee and also represents the Committee on appropriate occasions. That role is established by the Presidential Executive Order. So, it is the law. The chair is bound by the same restrictions as the Committee members are in relation to the discussing the recommendations. The buck stops at the President. He can act on the report or delegate it to an official in the federal government to act upon it.

Sally Atwater shared with the Committee members that, in her role as Executive Director of the Committee, she is responsible for releasing the report to the public. She asked Ms. Mantoan for a target date. Ms. Mantoan stated that that issue would be resolved by policy folks at HHS, *i.e.*, the Executive Secretariat or the White House Liaison's Office. Again, Ms. Mantoan explained that the matter is a policy issue, not a legal one. She stated that after the report is cleared by HHS, it would go to the White House and probably go through OMB clearance.

Dr. Bouthilet pointed out that the President has selected the Secretary of HHS, Tommy Thompson, as the person to be responsible for the Committee. Sally Atwater, Executive Director, is the designated federal officer for the Committee. She represents the Administration.

Mrs. Will asked if a member can go to someone in the Department of Transportation, for example, and say "I'm Mark Gross, member of the Committee; these are our recommendations." Ms. Mantoan replied that it would be unethical for him to do that.

Claudia Coleman asked if it would be inappropriate for the chair to go to each agency head to provide some background information on the report and explain how our report tied the agencies together and into the New Freedom Initiative. Mr. Mantoan advised that the Secretary of Health and Human Services has the authority to assign additional advisory functions to this Committee, which is permissible under the Executive Order.

Annette Talis thanked Ms. Mantoan for clarifying the fact that members can, as private citizens, go out and talk about the recommendations. She asked if she, as editor of a magazine published by the Wisconsin association of School Boards, could attach the recommendations and say to them, "these are the recommendations that the Committee has made and there is a role of every school board in making this national agenda a reality. The President is going to consider these." She also asked if she could attach the companion booklet to the magazine and disseminate it with the magazine to every school board member in Wisconsin.

Ms. Mantoan again said that it would depend upon whether the documents had been cleared, *i.e.*, a matter of policy in the federal government; things go through many levels of clearances before they get disseminated to the public. The legal answer is "you can't release information that's not generally made available to the public that you got as a member of a committee. You are a special government employee and have some ethical obligations not to disseminate information that our agency would treat as non public." You are free to disseminate the report after it has been cleared for public dissemination. Ms. Talis asked if the accompanying letter could be on her school board association's letterhead.

Mrs. Talis said that the booklet and the report are one single document, with two parts. When will they know when the document is public? Ms. Mantoan reiterated that this is a policy matter; that the report and companion booklet have not been sent to the President and are not considered public documents at this point.

Nancy Blanchard asked "what does sent to the President mean?" Ms. Mantoan replied that, realistically, the Secretary of the Department of Health and Human Services will issue a letter to the President attaching the report and the brochure, saying here are the recommendations and the report from this advisory committee. At that point, it would have gone through all the clearance processes, and then it's out the door. It is a public document.

Sally Atwater reminded the members that subcommittee chairs signed the letter of transmittal of the report from the Secretary to the President.

Mrs. Will conveyed that the time frame for the reports to go to the President is generally six months.

Johnnie Burton asked why the report has to go to OMB. Ms. Mantoan could not answer that question, since it is one of policy.

Brenda Leath asked if the chair should explore about getting an Executive Order to allow the Committee to conduct research. Mrs. Mantoan referred Mrs. Leath to someone with the Department of Health and Human Services. Getting an Executive Order is not an easy task and would be a long term solution. It would probably be best instigated by the agency level and the Department of Health and Human Services interacting with the White House.

Jim Brett asked what procedures he should use if he is asked to speak to a disability advocacy group because he is a member of the Committee. What should he say about the recommendations? Ms. Mantoan repeated that he could not disclose information about the recommendations until the report has become public information. After the report has been issued, he can discuss the recommendations but must clarify that he is speaking in a personal capacity, not as a member of the Committee.

Mr. Gross suggested that such an invitation be vetted with the Chair. Ms. Mantoan concurred and said that he might have to get ethical guidance. However, if the report has been made public, then Mr. Brett is free to discuss it in his capacity as a member of the Committee.

Alvaro Marin inquired about the penalty for violating the rule and how does one get persecuted? Ms. Mantoan conveyed that people can sue the federal government for violating the Federal Advisory Committee Act; then we will get bogged down in litigation and possibly tax some of your resources. There may be some unfavorable press accounts. Advocacy groups are very much aware of FACA and they will use it to try to undermine the Committee.

Mrs. Will asked if the President of the United States is able to dismiss a committee at any point in his administration. Ms. Mantoan's reply was, "yes, with respect to an advisory committee, he can terminate it."

Mrs. Will assured the Committee members that she would do everything in her power to try to get the report from the Secretary of HHS to the White House quickly and possibly to OMB.

Full Committee Discussion of Criteria for Considering Focus Topics for 2005-2006

After an exchange of ideas by Committee members on how best to proceed in selecting criteria, it was agreed that before choosing objectives, the Committee should research what the intellectually disabled population is, where they are being served, and how they can be better served.

The members identified the following issues for consideration as focus areas for 2005-2006:

- Housing
- Employment
- Emergency Preparedness
- Standards for providers of care
- Health issues
- Dental care
- Training for caretakers of people with intellectual disabilities
- Aging of parents/caregivers of people with intellectual disabilities.
- Communication and capacity building across the state, local and federal levels of government
- Regulatory issues regarding insurance coverage
- Public Awareness
- Training and wages of direct support professional staff.

After a brief discussion, the members agreed to discuss the issues further in full committee meeting on Tuesday, September 28, 2004.

Dissemination of Report to the President

Chairperson Will introduced Chris Downing, Director, Office of Public Affairs, Administration for Children and Families (ACF), who coordinates all media activities for ACF.

Mr. Downing thanked Mrs. Will for inviting him to address the Committee and commended the members for the work they had done for the PCPID. He presented some ideas on how to market the Report to the President after it is officially released.

- Op eds to local newspapers
- Meeting with local TV stations
- Local radio
- Sunday newspaper inserts such as Parade Magazine
- Local Chambers of Commerce
- A potential news release announcing the release of the report to the public

Presenter/PCPID Dialogue

Mrs. Kim Porter-Hoppe shared with the Committee that she had already written letters to the editor in her local newspaper that had been printed and asked if she should have signed her letters as an individual or as a member of the PCPID. Mrs. Atwater conveyed that the Office on Government Ethics would make a presentation to the Committee the following day and that the question should be posed to them.

Mrs. Will asked if it would be possible, after the document is made public, for the Committee to request a meeting with editorial boards of certain newspapers such as the *Washington Post* or the *New York Times*. Mr. Downing replied that a press conference would not be in the best interest of the PCPID because it serves at the behest of the White House and gets its marching orders from the White House. He suggested that the Committee contact the White House on what it can and cannot do.

Mr. Downing mentioned that Al Hunt of the *Wall Street Journal* is very interested in this issue and that he might be a good first approach. He reinforced that local medium markets would be the most likely places that would warmly receive the Committee. Articles in local newspapers sometimes get picked up by the national media.

Kathy Hargett mentioned some names she would like to add to the data base for receipt of the reports. Sally advised that copies to state and local representatives would be sent from the PCPID office after the report has been officially released. PCPID has 3,000 copies of the technical report, 4,500 copies of the companion booklet and 500 CDs.

An exchange took place between Jim Brett and Chris Downing on the timing for conducting outreach to the various advocacy groups, doing the op eds and Sunday morning or local radio. Sally responded that she would push the report through the White House. Mr. Brett pointed out that the Committee would need help from other agencies and that having the Committee work in one direction is a priority.

Sally reiterated that the Committee acts in an advisory role and cannot implement the recommendations.

Chris Downing suggested coming up with a framework and perhaps talking points to make the pitch to folks. He offered to provide assistance to Sally and her staff on a draft dissemination strategy for approaching the media outlets.

Dr. Radar, *Exceptional Parent Magazine*, offered to make and distribute 100,000 copies of the report, which goes to every members of Congress. Dr. Bouthilet advised Dr. Radar that the President has up one year to report to Congress on the report and it would not be advisable to submit the report to Congress before then.

In closing, Mrs. Will again reviewed the list of focus topics that will be discussed and voted upon at Tuesday's meeting: Housing, Employment, Emergency Preparedness, Standards for providers of care, Health issues, Dental care, Training for caretakers of people with intellectual disabilities, Aging of parents/caregivers of people with intellectual disabilities, Communication and capacity building across the state, local and federal levels of government, Regulatory issues regarding insurance coverage, Public Awareness, and Training and wages of direct support professional staff.

The meeting was recessed to reconvene on Tuesday, September 14, 2004.

Tuesday, September 14, 2004

The PCPID meeting was reconvened at 8:43 a.m.

Chairperson Will introduced Randy Hall, Attorney, Ethics Division, Office of the General Counsel, U.S. Department of Health and Human Services, who would help explain some of the ethical issues that affect the Committee members.

Mr. Hall provided an overview of ethics guidelines under 18 U.S.C. 208(a). All special government employees (SGE's) are required to file a confidential financial disclosure (Form 450) annually. If there is a potential conflict of interest, they must request a waiver. Interests of any spouse, minor children, employer or organization where an employee is an officer, director, or trustee, all financial interests are attributed to the employee; Mr. Hall next discussed the rules that apply to the members, both while they are employed and after they leave the federal government. An employee may not participate in any matter that would affect his financial interest. The best way to avoid a conflict of interest is disqualification or recusal; or, in the alternative, a waiver.

Mr. Hall also discussed briefly 5 C.F.R. § 2635-2640 which apply to diminimus waivers, where one can participate if his interest is \$25,000 or less and the product or issue would not directly affect the member.

There is a special rule for FACA participants, where you may participate in any particular matter of general applicability where the disqualifying financial interest arises from your non-federal employment. That means if the only interest affected may be who you work for on the outside, you are allowed to participate. In other words, if it affects your employer, you're allowed to be on the Committee. But, if you own stock in that company and it's going to affect your personal financial interest in that stock, you can't do it.

He emphasized representational restrictions under 18 U.S.C. §§ 201, 203, 205 and 208, which are criminal statutes. A Committee member cannot go out and represent to somebody in front of the government for the same things that he or she is doing for the Committee. Section 203 deals with receiving compensation for representation, *i.e.*, acting as an agent or attorney before an agency in a specific party particular matter that a member has worked on personally and substantially for the government. That means that if a member is a government employee, he cannot also be representing somebody before the government on the matter that he is working on, including matters that are pending.

In addition, a Committee member cannot switch sides. For example, when a special government employee leaves government service, he cannot represent anyone else to a court or agency in a specific party matter that the SGE worked on while with the government for one year after leaving government service. In other words, he can't come back in against the government on the other side.

Mr. Hall also discussed limitations on the acceptance of gifts, misuse of position, endorsement of products, services or enterprises, use of title, publications and disclaimers, foreign gifts and declarations, fundraising, solicitation of funds and disclosure of nonpublic information. Detailed information on these issues was provided in the handouts. He encouraged members to contact the Office on Government Ethics if they had any questions regarding possible conflicts.

Presenter/PCPID Dialogue

Dr. Appareddy asked if she could serve on an advisory committee with a foreign government without receiving compensation. Mr. Hall replied that the only issue would be if there is a conflict with her role as an advisory committee member.

Mrs. Will asked if a member could give a lecture at a foreign public university and, if so, could they get reimbursed for travel. Mr. Hall said that they could receive reimbursement for travel but could not receive compensation. Several factors are involved, such as whether reimbursement is coming from the university or the foreign government or what the foreign government's ties to the university are. All of this would have to be evaluated. However, if it is considered to be coming from the foreign government, payment cannot be accepted.

Another restriction is that a member cannot participate as an expert witness in connection with any matter or proceeding that he or she works on as a SGE, except for the United States. There is also a prohibition against lobbying, 18 U.S.C., 1913, which is a criminal statute. Specifically, as a special government employee, a member cannot lobby because it would be using government money to lobby. That does not mean that a member cannot make a presentation to people. He may give facts on what the provisions are, but cannot encourage people to lobby for it.

Claudia Coleman asked for clarification between educating and lobbying. Her Subcommittee is trying to create interest in the intellectual disability community and would like to inform people within the government and different agencies as to what is going on. Mr. Hall explained that if it's factual in nature or educational, then that is allowed. When you take a position and want people to support for that position, it is lobbying which is not permissible.

Jim Brett asked if the members were restricted from advocating, educating and promoting their recommendation on the qualified disability savings account. Mr. Hall's response was that members can only provide factual information because they are not allowed to release nonpublic information. If the information has not been released to the public, members are not authorized to release it. Once the President reviews the report and decides that it will go out to the world, then it is public information. Specifically, factual data would be:

- Status of the report
- Where it is
- Progress on the report
- Number of meetings held

Ed Mambruno noted that, as the Committee is meeting in a public form, the public is not under the same obligations that the members are. How do they respond if the public looks to the members for information they have received in a public forum?

Mr. Hall explained that, while the meetings are public, the report itself is not a public document. The final determination of what the report will say is not public. Therefore, the issues can be discussed but the final outcome cannot be discussed until the President has reviewed the report. He has up to one year to review it and send his recommendations, if any, to Congress.

Kim Porter-Hoppe asked Mr. Hall for clarification on whether members could have a dialogue of what is in the report, once it is in the hands of the President and becomes a public document. Members want to share information with the public and they need clear guidelines.

Mr. Hall reiterated that anything that is available to the public can be discussed. They were in on the public meetings and the information is available in the minutes. Only the issues may be discussed, until the report has become a public document.

Karen Staley stated that it is the duty of the citizen political appointees to work on the politics of the United States and get people around the policy ideas.

Mr. Hall reminded Mrs. Staley that unless members are representing the Committee on their views, the views they express are their own. He asked the members to remember the use of their titles and when they talk to people they should make it understood that they are discussing their own views, not representing the Committee.

The Chair thanked Mr. Hall for his presentation.

The Chair introduced Dr. Roy Grizzard, Assistant Secretary, Department of Labor, and asked him to speak about emergency preparedness for people with intellectual disabilities.

Dr. Grizzard provided an update on the Department of Labor's work on emergency preparedness. The Department reviewed statistics from the Harris Survey of the level of comfort of people with disabilities and felt that it would be important to improve on the safety aspects in the workplace.

There are approximately 120,000 federal employees with disabilities across the country. In December, the DoL had a seminar on emergency preparedness. They had experts from EMS first responders, the police, emergency preparedness people and others. He handed out a report to the Committee members on the outgrowth of that seminar.

Dr. Grizzard mentioned that Bill Kiernan and he have been working with the University of Massachusetts and the New England Council in making connections between the business community and the disabled community in recruiting workers who are disabled. The business community is advocating the idea of hiring people with disabilities.

Chairperson Will shared her follow up discussion with Mr. Hall regarding discussion of the report. Since the Committee has discussed certain recommendations in a public form and voted to make the recommendations in a public form, Mr. Hall concluded that since the recommendations are likely to be in the report, that information can be conveyed to the public in discussions by members. However, members cannot go through specific recommendations.

Full Committee Discussion for Selecting a Focus Topic for 2005-2006

Discussions resumed on selecting focus topics for 2005-2006. Mrs. Will referred to the issues that had been discussed the previous day. After lengthy discussion, the list of topics was narrowed down to dental care, health care, emergency planning and training of care giving providers. Mrs. Will advised the Committee that after a short recess and comments from the Commissioner of the Administration on Development Disabilities, the discussions on focus topics would continue.

United Nations Disability Treaty

Mrs. Will introduced Pat Morrissey, Commissioner of the Administration on Developmental Disabilities. Ms. Morrissey briefly discussed her recent two week visit at the United Nations as a member of the U.S. delegation to the United Nations participating in the development of an international treaty on civil rights for individuals with disabilities. Her delegation held a briefing on U.S. laws. Ms. Morrissey described the three major grant programs funded through the Developmental Disabilities Assistance and Bill of Rights Act – State Developmental Disabilities Councils, University Centers on Developmental Disabilities, and State Protection and Advocacy Systems. The U.S. civil rights law, especially the ADA, has become common language across the UN countries. Approximately 190 countries were represented. Over 100 nations debated the scope and structure of civil rights for individuals with disabilities. Ms. Morrissey has written a report on the outcomes of the meeting which she will share with the Committee.

Mrs. Will invited Ms. Morrissey to participate in the Committee discussion of focus topics of the PCPID for the years 2005-2006.

How RSA Relates to Employment of People with Intellectual Disabilities

The next speaker was Joanne Wilson, Commissioner, Rehabilitation Services Administration, Office of Special Education and Rehabilitative Services (OSERS), United States Department of Education.

Mrs. Wilson thanked the Committee for inviting her to speak. She began her presentation by describing the book and movie, *Seabiscuit*, which was written by a person with disabilities and based on a true story. *Seabiscuit* is a story about a colt that was trained to lose races so other horses could see what it was like to win. Along came a trainer, an owner and a jockey, and they saw something inside *Seabiscuit's* heart and his spirit that no one else saw. They worked with him and made him into one of the finest race horses of all times.

Ms. Wilson compared the true story of *Seabiscuit* to the work that people in the field of rehabilitation and others do. They are the trainer, the owner and the jockey. They see something in folks with disabilities and figure out a system that will work better to serve them and make them champions. First, they must develop their own philosophy about disability that goes beyond the norm of what others see. Second, they must convince people with disabilities that they can be something else. Third, they must change the public views that people with disabilities are underdogs and see them in a different light.

Mrs. Wilson explained the purpose of the law that governs the Vocational Rehabilitation System which is (1) to empower people with disabilities; (2) to maximize employment, independence, economic self-sufficiency and (3) to help them lead full lives in an integrated and inclusive setting. The law also emphasizes things like individualized services, helping people reach their full potential, providing comprehensive services, and providing choice for individuals.

When Mrs. Wilson accepted her position as Commissioner of Rehabilitation Services Administration, she decided that the first thing she had to do was to develop some principles. She developed six:

1. Belief that people with significant disabilities can go to work and have high quality, meaningful employment in an integrated setting, have real competitive employment, and lead full, independent lives and lead lives where they are happy and fulfilled.
2. Change the misconceptions that exist about people with disabilities.
3. People with disabilities have a right to choose what they want to do with their lives, who they want to provide service for them, and what kind of services they want.
4. Empower people with disabilities by giving them the equipment, services, education, training, confidence and high expectations so that they can get a job and lead an independent life.
5. Streamline the bureaucracy, paperwork and long waiting periods.
6. Work with private providers, state partners, local partners and other organizations for people with disabilities.

Ms. Wilson extended her compliments to Chairperson Madeleine Will and the significant changes she had made for people with disabilities in the past; for example, supported employment was introduced into the Public Vocations Rehabilitation system, money was set aside for supported employment to help serve people with the most significant disabilities; options were provided to choose community inclusion and integration into society. Thanks, to Madeleine's efforts, we have about \$2.6 billion in grants that is made to 80 agencies

around the country. About 21.3 percent is put up by the states. There is about \$38 million in supported employment funds which is provided to states to run their programs and provide supported employment. The states work with private providers in their states to set up supported employment systems. They can use the money for about 18 months. After that, other sources of funds need to be found. Ms. Wilson handed out some data that shows where the money goes. It also shows outcomes from the year 2000 to 2003.

- 7.3 percent of people with intellectual disabilities are served with supported employment funds.
- Approximately 44.1 percent of people with specified learning disabilities are served.
- 25 percent of transition students benefit.
- 75 percent of people in supported position earn between \$5.15 and \$7.99 per hour.
- 17 to 18 percent work full time.

Ms. Wilson asked for the Committee's help in figuring out what to do after the 18-month period expires and these people leave the system. For example, natural supports, waivers, Medicaid waivers, and the ticket to work program.

RSA has also been emphasizing transition services – services that are seamless for kids coming out of school and going into adult life.

- In the 1960s the earliest populations were folks with intellectual disabilities. Transition services were starting to be provided before it became popular.
- In the 1970s, Special Education and Voc Rehab began putting out joint guidance on how they could work together.
- During the 1980s, systems change grants were given to states.
- In the 1990s, regulation of the law began, *i.e.*, regulations of the law which says that rehabilitation needs to begin prior to the exit year of school to prepare them to shift over into the next programs and look at employment.

Currently, RSA is trying to strengthen all those regulations. There is currently a proposal on the Hill that would apply the regulations to kids at age 14.

- About 13.6 percent of the kids in the rehabilitation system are transition-age children.
- Two thirds of those come from Special Education
- About 63 percent end up with employment.

RSA will have a national conference in 2005 on transition, specifically geared for the public rehab system to see how they can put forth a better best practice that works. They are also placing emphasis on mentoring programs; joint monitoring of states and doing some pilot literacy grants.

Presenter/PCPID Dialogue

John Benison, representing the Department of Transportation (DoL) stated that the DoL is pushing to hire people with targeted disabilities and intellectual disabilities. They have found that getting the Schedule A letters from the state and local voc rehab agencies is a problem. It also hinders the potential appointee due to lack of understanding of the letter. He asked if RSA has any plans to address that issue.

Ms. Wilson said that the rule on that has changed and now agencies other than voc rehab can certify that a person has a disability.

Annette Talis asked if the majority of people with learning disabilities are classified as having literacy-based, functional disabilities. And, is RSA partnering with the Department of Education to see what schools can do to provide skills? Ms. Wilson replied that early training is very important and mentioned that the Office of Rehabilitative Services (RSA) in the Office of Special Education and Rehabilitative Services (OSERS), the Office of Vocational and Adult Education (OVAE) and the National Institute on Disability Research and Rehabilitation (NIDRR) all of which are part of the Department of Education and they all work closely with Special Education. The Assistant Secretary looks at all of their policies, all of which compliment each other.

Karen Staley asked if RSA is looking at working with people in the micro-enterprise industry. Ms. Wilson stated that they are getting the word out to the field and state agencies that this is an important issue, including private and-self employment.

Jim Brett asked if follow up had been done to determine how many people are still in the workforce. As she did not have the data with her, Ms. Wilson said she would provide the numbers to the members at a later date.

Mr. Brett also asked what the main barriers to preventing these numbers from increasing further: economy, lack of training, or lack of transportation. Ms. Wilson replied that it is a little bit of all three.

Chairperson Will asked if Voc Rehab funds could be used to support individuals in postsecondary programs under IDEA. Ms. Wilson confirmed that they can and provided statistics on outcomes of the programs:

- One out of 25 college students are people with learning disabilities.
- The dropout rate is about 46 percent for people with disabilities, opposed to 33 percent for the non-disabled

There being no further questions, Mrs. Will thanked Ms. Wilson for her presentation.

Future Initiatives

After a short recess, the meeting was reconvened and Mrs. Will recognized Stephanie Lee, Director, Office of Special Education Programs, a guest. She explained to Stephanie that the committee had discussed focus topics for 2005-2006 and had reduced the number of topics to five: Emergency Preparedness; comprehensive health; dental care which could be folded into comprehensive health care; housing, and training of direct support personnel.

Pat Morrissey conveyed that the Department of Labor has an initiative on training for direct support personnel. She mentioned that the Administration on Developmental Disabilities had a two-part conference on a direct care workers initiative in the winter of 2002. The Department of Labor launched this initiative in early 2003.

The Committee exchanged views on the five categories of emergency preparedness; dental care; housing (to include aging); comprehensive health care (to include dental care); and training of direct service professionals. Kim Porter-Hoppe asked for clarity on the original topics that include subgroups and stated that since emergency preparedness is already on a fast track by another agency, she felt that the PCPID could not provide advice in a timely manner. Comprehensive health care had subgroups of health care, dental care and mental health. The housing category dealt with adult work life, as well as the aging population and training included direct support personnel and emergency preparedness. She suggested going back to the three general topics.

Stephanie Lee stated that it was her understanding that Homeland Security had asked for PCPID's help with emergency preparedness. She felt that if a government agency asked for help and was willing to provide funds for it, then PCPID should keep it on the radar screen. She was particularly concerned about what would happen to her own daughter if there were a terrorist act.

John Benison seconded Stephanie's point. He shared with the Committee that he has been very involved in the government-wide emergency preparedness initiatives. The directive in the Executive Order was that people with disabilities need to be fully integrated into emergency preparedness plans. The federal government really needs the help of this Committee in learning what the unique needs of people with intellectual disabilities are so that an education initiative can be put to the local communities and to all people who would potentially be working on emergency preparedness. How do we address the needs of these people in an emergency situation?

Mrs. Will felt that the Committee should explore some of the issues and do some fact-finding to determine the viability of the issues.

The following topics of focus for 2005-2006 were agreed upon:

- Emergency Preparedness: Kathy Hargett (with Michael Rogers)¹
- Dental Care: Jim Brett (possibly included with health care)
- Housing: Gene Stallings (including aging issues)
- Direct Support Professional Training: Karen Staley
- Comprehensive Health Care: Brenda Leath (and Dr. Appareddy)

At the request of Karen Staley, Mrs. Will said that an email would be sent to members the following listing the selected topics and individuals who expressed an interest in working on them. The email would be followed up with a conference call to discuss the matter further.

Sally Atwater also reminded members that all correspondence relating to PCPID business was subject to the Freedom of Information Act (FOIA). It is important that all messages be written in a somewhat formal, professional style. The use of discretion in the way members communication with each other and staff is also important because it is all public information.

Mrs. Will acknowledged and thanked Amy Filko, HHS graphic artist, who helped so much with the design of the companion booklet.

Claudia Coleman asked that the Committee one or two people work with the staff and with Madeleine Will to work on the education process of moving our report and companion booklet forward; to stay proactive and keep things on track. Mrs. Will assured Mrs. Coleman that the issue would not be dropped.

Wrap-Up and Next Steps

A brief discussion took place on a possible change in Administration and its effect on Committee members.

Members also discussed the per diem and reimbursement process for their attendance at quarterly meetings. Some members received a check for \$50 without explanation. They asked for clarity on whether or not they should turn in receipts for expenses. In addition, members are supposed to be paid \$100 per day, in addition to expenses (per diem). Karen Staley said that she had never been paid. Sally Atwater will address this issue with staff.

Action Items

Per diem reimbursement for PCPID member attendance at quarterly meetings
Moving the Report to the President forward
PCPID focus topics for 2005-2006:

¹ PCPID member Michael Rogers was not able to participate in the voting of selected issues. However he has previously indicated a desire to work on the Emergency Preparedness issue.

- Emergency Preparedness
- Dental Care
- Housing
- Direct Support Professional Training
- Comprehensive Health Care

Mrs. Will announced that the next quarterly meeting would be held in January or February 2005. The meeting was adjourned at 1:38 p.m.