



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

~ Minutes ~  
June 16-17, 2011 Meeting

**Participants**

**Ex officio Members and Representatives:**

Michelle Aronowitz

*Representing the Honorable Shaun L.S. Donovan, Secretary, U.S. Department of Housing and Urban Development*

Mary Kay Mauren

*Representing the Honorable Jacqueline A. Berrien, Chair, Equal Employment Opportunity Commission*

Richard Balkus

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

Alexa Posny

*Representing the Honorable Arne Duncan, Secretary, U.S. Department of Education*

Jewel Bazilio-Bellgarde

*Representing the Honorable Patrick Corvington, Chief Executive Officer, Corporation for National and Community Services*

Margaret Schaefer

*Representing the Honorable Janet A. Napolitano, Secretary, U.S. Department of Homeland Security*

Henry Claypool and Dr. Rosaly Correa

*Representing the Honorable Kathleen Sebelius, Secretary, U.S. Department of Health and Human Services*

William D. Falsey

*Representing the Honorable Kenneth L. Salazar, Secretary, U.S. Department of the Interior*

Caffin Gordon and Michael Caliendo

*Representing the Honorable Raymond L. LaHood, Secretary, U.S. Department of Transportation*

Carl M. La Mell

**Citizen Members:**

James T. Brett, Chair  
Annette McKenzie Anderson, Ph.D.  
Peter V. Berns  
Clay Boatright  
Micki Edelson  
Ann Hardiman  
Alison A. Hillman de Velasquez

Carol Quirk  
Susana Ramirez  
Deborah M. Spitalnik, Ph.D.  
Lillian Sugarman  
Liz Weintraub  
Carol Wheeler  
Sheryl White-Scott, M.D.

**Guest Speakers/Presenters:**

Gail Bowles  
Kareem Dale  
Jill Eglé  
David A. Hansell

Mike McCauley  
Patricia Mantoan  
Naomi Miske

**Special Guest(s):**

Representative Rush Holt (NJ-12)  
Deputy Assistant Secretary Sue Swenson, OSERS

**Constituency Group Representatives:**

George Jesien, Ph.D.  
Margaret Dickinson, Ph.D.

**Other Guests:**

Charles Acree  
Ronald Austin  
Patrick Burns  
Dawn Carlson  
Jon Considine  
Jim Delver  
Amanda Mays  
Charles McKenzie  
Francis Parks  
Renee Pietranjelo

Sherrie Rudick  
Richard Ruiz  
Rita Stevens

Marcel Velasquez  
Molly Weingant  
Charlene Wells  
Kevin Wenzel  
Gillian A. White

**ADD-PCPID Staff:**

Sharon Lewis, Commissioner  
Zach Holler  
Kathryn Fialkowski  
Saud Jama

Madjid "MJ" Karimi  
Jamie Kendall  
Pamela O'Brien

Laverdia Taylor Roach  
Bethany Swanson

Genevieve Swift  
Sheila Whittaker

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

**Greetings and Call to Order**

**Sharon Lewis, Commissioner and Designated Federal Official**

The June 16-17, 2011 meeting of the President's Committee for People with Intellectual Disabilities (PCPID) was called to order by Sharon Lewis, Designated Federal Official, and Commissioner of the Administration on Developmental Disabilities (ADD), who welcomed meeting participants. Commissioner Lewis gave a description of the purpose and history of the Committee from its inception as President Kennedy's Panel on Mental Retardation in 1961. She detailed, some of the major themes considered by the Committee in the past, including criminal justice, education, and employment. Commissioner Lewis then turned the meeting over to Acting Assistant Secretary for Children and Families, David Hansell.

**Welcome**

**David Hansell, Acting Assistant Secretary, Administration for Children and Families**

Acting Assistant Secretary Hansell welcomed the meeting participants, on behalf of Secretary Sebellius, and congratulated new appointees to the Committee. Mr. Hansell expressed appreciation to Commissioner Lewis, Ms. Laverdia Roach, and the members of the PCPID staff for their support of the Committee. He gave a brief presentation citing the Committee's achievements over the past 50 years and pledged the full support the Committee's actions in the pursuit of a future where people with intellectual disabilities have full access to the privileges, rights, and advantages of American citizens. Mr. Hansell expressed delight that one of his last actions as Acting Assistant Secretary would be to join the Committee at this meeting. He then presented Mr. Kareem Dale, Associate Director of the White House Office of Public Engagement, and Special Assistant to the President for disability policy, to lead the swearing-in ceremony.

**Swearing-In Ceremony**

**Kareem Dale, Associate Director and Special Assistant to the President**

Mr. Dale expressed the commitment of President Barack Obama and his Administration to people with disabilities, and described several recent achievements that seek to benefit people with Intellectual and Developmental Disabilities (IDD). He noted the importance of the Committee's work to the President's continuing efforts to support people with intellectual disabilities and his desire to see more self-advocates as future appointments to this current Committee. Mr. Dale expressed appreciation for the Committee's past, present, and future service to people with intellectual disabilities, after which he prepared to lead the new appointees in repeating the Oath of Office. Just as the new appointees prepared to swear the oath, Representative Rush Holt (NJ-12) entered the meeting room and was acknowledged by Mr. Dale, who then proceeded to lead the new appointees in repeating the oath.

(Brief recess)

## **Self-Introductions**

Mr. Jim Brett, Committee Chair, greeted members and introduced himself. He asked each member of the Committee as well as Commissioner Sharon Lewis, Ms. Laverdia Roach, and “MJ” Karimi to give self-introductions that included their background in the field and the work done by their organizations or agencies.

Following the self-introductions, Dr. Deborah Spitalnik suggested inviting a representative from the Environmental Protection Administration (EPA) to serve as an ex-officio member of the Committee. She noted that the EPA does work in the field of health and the impact of toxins and other environmental issues, which may have a relationship to intellectual disabilities. Chairman Brett responded that this was a good suggestion, which could be explored further at a later time.

Mr. Brett concluded this section of the meeting by giving details about a small reception for new members and their families and guests in the Rosa Parks Room of the Hubert H. Humphrey Building.

(Mid-Morning Recess)

## **AFTERNOON SESSION**

Chairman Brett opened the afternoon session by announcing the agenda, which included presentations by the leadership of different agencies within the executive branch. The Chair stated that it was an opportunity to meet key policy makers who play major roles in daily operations of the Administration. He then introduced the White House Liaison, from the Office of the Secretary of Health and Human Services, Mike McCauley, who gave an update on his role and responsibilities.

### **Role of White House Liaison**

#### **Mike McCauley, White House Liaison**

Mr. McCauley thanked the Committee on behalf of the President and the Secretary and the leadership at the Department of Health and Human Services (DHHS). He told members that the Administration appreciated their willingness to serve.

Mr. McCauley stated that there is a White House Liaison at each cabinet agency, with responsibility to advise cabinet secretaries and senior leadership and manage the political personnel program. He mentioned that his office advises and assists the HHS Secretary and her Chief of Staff on the management of committee activities, including all federal advisory committees within the Department’s jurisdiction, as well as the 250 Presidential Advisory Committees similar to PCPID. Mr. McCauley reported that an important change to the PCPID charter was made, to align the Committee with the ADD. The Secretary and the White House made the decision because ADD and PCPID have similar missions. The PCPID Executive Order

charters the Committee to promote full participation of people with intellectual disabilities in their communities through the development of an annual report, which is consistent with the mission of ADD. Mr. McCauley continued that this realignment will help make the important work that the Committee does more effective, knowing the strength that will come from combined efforts. He shared that he is the sibling of an adult with Down Syndrome, and said that he personally appreciates the Committee's work and services.

Dr. Spitalnik thanked Mr. McCauley for all of his efforts. She pointed out that the 50<sup>th</sup> anniversary of the Committee, when President John F. Kennedy first appointed the Blue Ribbon Panel, would be on October 11, 2012, and recommended placing it on the collective calendar and consciousness. Mr. McCauley thanked Dr. Spitalnik for the reminder and stated that the Administration would take the Committee's 50<sup>th</sup> anniversary into consideration, as it works with the members to plan for future activities.

In response to an inquiry from Ann Hardiman, Chairman Brett asked Commissioner Lewis to clarify the role of the National Council on Disability (NCD) in relationship to PCPID. Ms. Lewis noted that NCD was established under the Rehabilitation Act and is an independent organization that operates as a board with full-time agency staff that looks at disability issues across the government and is charged with advising the Congress, as well as the President, as opposed to PCPID, which is primarily to advise the Secretary and the President.

Ms. Roach added that NCD is one of the 13 PCPID ex officio members and organizations. The NCD representative to the Committee is Mr. Gary Blumenthal.

Ms. Quirk inquired if there was a vetting process for the Annual Report to the President. Commissioner Lewis responded that PCPID is an independent Committee and will establish the report and the recommendations that will go through a nominal legal clearance process, because the report is subjected to the Freedom of Information Act (FOIA) regulations. She asked Laverdia Roach if she had anything to add. Laverdia stated that, as the report goes through an internal Departmental clearance, there should be no substantive change to the Committee's approved draft, unless it is discovered that there is some statement that is inconsistent with departmental policies, at which time the draft would have to be modified. Ms. Quirk asked if the Department was DHHS. Laverdia answered affirmatively, but advised that all ex officio agencies, listed in PCPID Executive Order must also approve the report.

Commissioner Lewis stated that President Obama's Administration is committed to InterOperability and collaboration across agencies, in terms of clearance processes. She noted that, because this will be the Committee's first report under this Administration, whether or not the clearance process vets out through agencies remains to be seen. The Commissioner stated that it was a policy decision by the Administration to ensure that agencies be given the opportunity to comment on various pieces of testimonies, policies, proposed rules, before "they go out the door."

Chairman Brett expressed the Committee's appreciation to Mr. McCauley for his update and time.

**PCPID Procedures Manual**  
**Laverdia Roach, PCPID**

Chairman Brett introduced Ms. Laverdia Roach who has served the Committee as an Acting Executive Director since January 21, 2009. Ms. Roach provided an extensive overview of PCPID procedures. She mentioned that the purpose of the presentation was to share information developed over five decades about PCPID's mission, role, and organization structure, functioning, and mandate to present an Annual Report to the President.

Ms. Roach stated that a major goal is to have the Committee function as efficiently as possible in executing its mission to be the voice for individuals with intellectual disabilities, and to improve the quality of their daily lives. She reminded members that although their expected tenure is two years, they serve at the pleasure of the President.

Laverdia discussed the Committee's legal responsibilities in compliance with the Federal Advisory Committee Act (FACA), its history, and the roles and responsibilities of the Committee Chair (see attached document). In summarizing the primary responsibility of the Committee, she urged members to remember that they have one responsibility: that is to prepare the Annual Report to the President. The PCPID Executive Order requires the Committee to prepare a report to the President to apprise him of the status of the national efforts to prevent and ameliorate the effects of intellectual disabilities and to improve the quality of life experience by people with intellectual disabilities. Ms. Roach encouraged Committee members to first determine the focus areas that they believe are currently impacting people with intellectual disabilities in a way that prevents them from enjoying life to the fullest, and then to select from those focus areas, topic or that they believe will make the greatest impact. She added that there has not been a printed report since 2004, and that this Committee's report will be the first presented to President Barack Obama.

After summarizing the review process for the report, Ms. Roach invited questions.

Ms. Carol Quirk asked if the last report, in 2009, went to the President. Ms. Roach responded that it went to the White House, but was never published. Carol asked why it was not published. Laverdia expressed that it was the policy of the last Administration to have reports of the Committee "on hold" until the White House approved printing/publication. The President had up to two years to approve the publication of the report.

Dr. Spitalnik asked how often the full Committee will meet per year to work on the report. She also asked if there were any financial resources available to the Committee. Laverdia replied that the PCPID Charter calls for no less than two face-to-face meeting per fiscal year. Chairman Brett remarked that it used to be quarterly and Ms. Roach concurred, suggesting that the Committee meet again in the fall before the end of the fiscal year, which would constitute the two meetings for this fiscal year.

Dr. Spitalnik asked if it would meet before September 30<sup>th</sup>, Ms. Roach responded affirmatively. Laverdia also stated that part of the rationale for the realignment is so that PCPID may have fiscal and personnel resources available that it did not have previously.

In response to a question regarding the frequency of Committee Meetings via conference call, in addition to the two face-to-face meetings, Laverdia stated that most of the PCPID subcommittees (if members agree to form subcommittees) have customarily meet via audio conferencing. She

noted that, in such instances, individual members need only place a call to the PCPID office requesting the opportunity to meet via telephone conferencing, and staff will make arrangements.

Ms. Weintraub asked about the language in the Report to the President. Ms. Roach responded that all PCMR-PCPID Reports are 508 compliant, and in lay language easy for self-advocates to read and comprehend.

Mr. Boatwright asked about the timeframe in which the Annual Report to the President would be due. Laverdia clarified that the report is due by the end of each calendar year. She noted that because of the extensive review by ex officio agencies, however, it is prudent that the final draft of the report be ready by mid to late November. Ms. Wheeler asked a similar question regarding the timeframe to have this particular report ready. Laverdia replied that for this report mid November would be an ideal time. At the end of her presentation, Ms. Roach stated that the Committee will not meet again as a full body, face-to-face, until the fall. The audio conferencing options will be available for interim meetings.

### **Approval of the Agenda James Brett, PCPID Chair**

Chairman Brett asked for a motion to approve the agenda. Mr. La Mell made the motion which was seconded by Dr. Spitalnik. The motion was carried, without discussion, and Chair declared that the agenda was unanimously approved.

### **Federal Advisory Committee Act (FACA) Patricia Mantoan, Office of the General Counsel**

Ms. Mantoan started her presentation by explaining the importance of FACA requirements and the statute governing Federal and Presidential Advisory Committees. She explained that the purpose of FACA is to bring transparency and openness to the advisory Committee process and to allow public participation.

Ms. Mantoan outlined some of the statutory requirements of FACA and explained that the burden for compliance rested with the agency, not with the Committee members. She highlighted types of meetings that are not required to be public; including, administrative and subcommittee meetings. She defined subcommittees, as consisting of two or more members to draft reports for presentation to the full Committee at an open meeting; and stated that subcommittees are not legally required to have open meetings, as long as their role is strictly to advise the larger parent committee. Ms. Mantoan emphasized that a subcommittee would be in violation of the law if it prepares recommendations and shares them directly with the President or a Federal Official without the approval of the full Committee. She explained that the Committee's annual report is filed with the Library of Congress to allow researchers to have access to the past reports. Ms. Mantoan closed her presentation by stressing the importance of compliance with FACA requirements, and then invited questions.

In response to Dr. White-Scott's question regarding why eight copies of the Committee's report is filed with the Library of Congress, Ms. Mantoan replied that it is a quirk in the Federal Advisory Committee Act which actually specifies eight copies.

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

## **Ethics**

### **Naomi Miske, Office of the General Counsel**

Ms. Miske began by defining a Special Government Employee (SGE) and noting that SGEs have relaxed ethics rules when compared to fulltime Federal employees. She encouraged the members to take a look at the ethics rules and regulations. She 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. Ms. Miske noted that these rules are codified in a criminal statute and that violation of the rules could come with fines and possibly prison terms, and 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. She advised Committee members to contact their ethics official, immediately, if they feel that they may have a possible conflict.

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

After Ms. Miske's discussion of 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. Members asked for additional clarification on several issues and Ms. Miske suggested that they notify her office, directly, with questions about particular activities that may potentially be in conflict with the ethics statutes and guidelines. In response to a question regarding exception for gifts, Ms. Miske noted there is an exception for gifts worth \$20 or less offered to you by a prohibited source. That is somebody who is impacted by the performance of your duties. No more than \$50 from a source per year. In response to a question regarding press, Ms. Miske advised before a member gives an interview to the press, they should contact public affairs and get authorization from the Committee Chair. Laverdia Roach offered to provide members with the contact information for Mary Ann McMullen and staff of the Office of Public Affairs, Administration for Children and Families.

Commissioner Lewis followed up by asking the members to consider whether the press is contacting them specifically because of their role as a member of PCPID or, is the fact that they are a member of the Committee ancillary to the conversation.

In response to Dr. Spitalnik's question regarding PCPID's merge with ADD, Commissioner Lewis responded that when she talked to General Counsel about this previously, she understood that each member serves on the PCPID as an individual, not representing their own organization. She added that, as long as members are declaring, conflict of interest in terms of any matter before PCPID, as Naomi is describing it, they will be fine. Commissioner Lewis stated that the

decisions of this Committee will not affect ADD funding resources in any manner, other than it would any other Advisory Committee.

Ms. Miske advised member “if you are asked to speak as a member and authorized to speak as a member of the Committee in your official function, you are invited to speak at a conference, and you are authorized to do so, you may accept free attendance and food at the conference the day you speak.”

In response to Mr. Boatright’s question, when testifying before State legislatures if he could list this in his credentials, Ms. Miske answered affirmatively.

In response to Chairman Brett’s inquiry regarding supporting pieces of legislation in the legislature, Ms. Miske replied that you can do it in your personal capacity and you should not do any of that on Committee time or on agency’s property.

In response to a question regarding speaking at nonprofit functions, Ms. Miske stated it was allowed. She stated PCPID primarily works on what we call general applicability matters. Naomi pointed out that the Committee members are prohibited from acting as an agent of a foreign principal or a lobbyist. She added that the statute does not prohibit the members lobbying in their personal capacity for something that they are passionate and acknowledgeable about. She also shared with the members that while they are in government building, using the government resources, they may not engage in partisan political activities.

Chainman Brett asked if a Committee member should accept invitation to speak to an outside group because of the title he or she holds at PCPID. Ms. Miske responded, “Yes,” many outside groups will invite Committee members to speak just because of their official positions. There are, however, rules on compensated teaching, speaking, writing, and expert witness. There are differences in the kinds of waivers that DHHS issues in such circumstances. There is not a good rule for ethics because so much of it depends on appearances, she added. Ms. Miske stressed that the PCPID DFO, Sharon Lewis, is the first line of defense here. ACF Deputy Ethics Counselor is Mr. Jason Donaldson and Ms. Donnell Savage is the ACF ethics contact person. The Designated Agency Ethics Official at DHHS is Mr. Ed Swindell. Ms. Miske thanked the Committee members and staff for this training opportunity.

Chairman Brett then represented the next guest speaker, Ms. Gail Bowles, Federal Agency Travel Administrator (FATA) for ACF. Gail shared her understanding that members will not receive individualized travel cards, as they are considered “invitational travelers.” ACF has an e-Gov travel service, called GovTrip, which enables staff to reserve Committee members lodging, airfare, rail, rental cars, etc. Ms. Bowles referred the Committee members to a section in their binders that included the “PCPID Travel Manual.” She added that the Committee members are expected to use a method of travel that is most advantageous to the government. In cases where there is a special need, such as a medical issue, members are required to submit a letter from their physicians, authorizing them to use the most costly method of transportation.

Ms. Bowles pointed out that the members’ per diem rates are determined by their official duty stations (home addresses). The GovTrip will automatically calculate the per diem rate. She stated that the members are expected to input their travel expenses that include receipts into GovTrip, five business days from their date of travel. Sheila Whittaker from the PCPID staff

will enter members' profiles in GOvTrip. As a lead FATA, Ms. Bowles is on call 24/7 to assist the members with their emergency needs. Staff will e-mail her Blackberry number to members.

Gail concluded her presentation by wishing all the PCPID members a safe trip as they maneuver back and forth from their duty stations to PCPID meeting sites.

**Overview of PCPID Alignment within HHS,  
Administration Agenda on Disability, and Wrap-up  
Commissioner Sharon Lewis**

Commissioner Lewis presented an overview of the PCPID alignment within HHS and the Administration agenda on disability. She started her remarks encouraging members to feel free to call her and Laverdia anytime that they have a question, and thanking the PCPID staff for pulling this meeting together on a very short timetable.

Commissioner Lewis stated that the primary focus of this Administration's activities related to people with disabilities falls into five categories. One of the most important priorities that the President Barack Obama set forward for people with disabilities is to increase employment opportunities. The President is committed to expanding access to employment for people with disabilities by ensuring that his Administration hires people with disabilities first and foremost. For example, seventy-five percent of the ADD hires have been individuals with significant disabilities. Commissioner Lewis note that Laverdia Roach has been the DHHS-ACF champion, leading the disability hiring initiative and working, collaboratively, with other leaders to bring Project SEARCH to the Department. Project SEARCH is an internship program for students with IDD in their final years of post-secondary transition, to ensure that those students have opportunities to participate in on-the-job work.

President Obama has issued an Executive Order that makes the Federal Government a model employer for person with disabilities. The Department of Labor's "Out is In" initiative identifies specific strategies to increase employment opportunities for people with disabilities within small businesses owned and operated by minorities. Commissioner Lewis stated that Joyce Bender from Bender Consulting has been working with the Office of Personnel Management (OPM) to ensure that people with disabilities are employed in the Federal Government. Additionally, starting last year, the Department of Labor, Bureau of Labor Statistics, for the first time began reporting employment of people with disabilities.

Commissioner Lewis expressed that President Obama has also made a commitment to expand educational opportunities for all people, including people with disabilities. The President is working hard on reauthorization of the Elementary and Secondary Education Act, to ensure increase support for the inclusion and improved outcomes of students with disabilities. The President is also working hard to ensure that teachers are prepared to meet the needs of diverse learners and let assessments more appropriately measure the performance of students with disabilities. He supports expended funding and increased enforcement for programs like the Individuals with Disabilities Education Act (IDEA) that ensures all students with disabilities have access and tools to succeed.

The third part of the Administration's agenda is support of the development and use of accessible technology. The President is committed to innovation and access to technology and supports the

passage of the 21<sup>st</sup> Century Communications and Video Accessibility Act. This is related to everything from making next generation emergency services accessible to people with disabilities, looking at television and the internet programming, and expanding access to close captioning and video description.

Commissioner Lewis added that the Comprehensive Health Care Reform has been on top of the President's Disability Agenda. As Secretary Kathleen Sebelius said at one of the ADD events, "when President Obama signed the Affordable Care Act into law last year, we not only achieved the healthcare goal that many had been seeking for years, but we helped fulfill the promise of the Americans with Disabilities Act 20 years after it was passed." Sharon noted that the Affordable Care Act breaks down the barrier and ensures that all individuals have access to healthcare by ending discrimination based on pre-existing conditions and caps on life-time benefits, starting in 2014, barring insurance companies from discrimination based on medical history or genetic information.

The Community Living Assistance Services and Support Program, the "CLASS Program," is a self-funded and voluntary long-term supports and services choice that would help people with disabilities remain at home and work. The establishment of the Community First Choice Option expands access to community-based attendant service and supports. Also, the establishment of standards for medical diagnostic equipment enables people with disabilities to have access to preventative care.

The fifth priority established by the President Obama revolves around the protection of civil rights and promotion of access to community living. The President has made a firm commitment to do more in terms of the enforcement of the Americans with Disabilities Act (ADA). People who are familiar with the collaborative work of Tom Perez, Sam Baganstaus, and the Department of Justice have seen evidence of that work.

Commissioner Lewis mentioned that the alignment of PCPID and ADD has been an important effort to work within the vision that the President and the Secretary have laid out as it relates to the Community Living Initiative. She stated that the purpose of Developmental Disabilities Act is "to assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence productivity, and integration and inclusion in all facets of community life." The Commissioner observed that this is consistent with the Committee's charge, through the Executive Order, that directs the Committee to "promote the full participation of people with intellectual disabilities in their communities." The bottom-line is that the message has been clear from individuals with intellectual and developmental disabilities and their family members; they want the opportunity to live in the community.

Commissioner Lewis acknowledged the following five goals:

1. Ensuring the rights of individuals with developmental disabilities are protected and preventing the abuse, neglect, and exploitation of such individuals
2. Empowering individuals with developmental disabilities and their families to be able to easily access home- and community-based services and supports that are self-directed and ensure opportunity for full community participation

3. Promoting employment first, as a key strategy for individuals with developmental disabilities to be contributing, productive, integrated members of society
4. Supporting the advocacy efforts of individuals with developmental disabilities throughout the developmental disabilities network
5. Establishing and maintaining the effective and responsive management of responsibilities under the DD Act

The Commissioner emphasized that the priority of the Committee will be getting the Annual Report to the President completed over the course of the next six months. She pointed out that the structure and the content of the report needs to be driven by all the Committee members. In response to the question, “who will pay for the report,” Commissioner Lewis responded, “It depends on how you want to define paying for the report. We have a limited budget for the operations of the Committee of about \$43,000 for the year, that includes all of your travel and everything related to operating the committee outside of staff time.”

Mid-afternoon of Day One, new Committee appointee, Liz Weintraub, arrived for the meeting and was sworn-in by Commissioner Lewis.

(Afternoon Recess)

## DAY TWO

### **Call to Order**

**James T. Brett, Chair**

The June 17, 2011 meeting was called to order by Chairman Brett who welcomed the Committee members. Meeting participants view a clip from the documentary film, “Life in the Shadows”. Following a brief discussion of the clip, Chairman Brett introduced Jill Eglé, Co-Executive Director of the Arc of Northern Virginia.

### **“Jill’s Journey” [Perspective from Self-Advocates]**

**Jill Eglé, Co-Executive Director, Arc of Northern Virginia**

Ms. Eglé detailed her struggle to find a career that, not only paid well, but one for which she also had a passion. She stated that the elements of a true career and successful passion are a supervisor, colleagues, supported job coach, family members and good pay. Jill explained that she found the most success in careers that she started as a volunteer with her job coach, which eventually progressed into a paid position without natural supports. She has worked with the Arc of Northern Virginia for almost five years as an administrative assistant, an advocate, and as co-executive director.

Ms. Eglé then described her work related to Rosa’s Law, which successfully replaced the negative label of “mental retardation” with a respectful term, “intellectual disabilities.” Her focus now is education of the community; especially individuals’ power, about intellectual disabilities and the work of the Arc (before her move to New Orleans).

When asked by Dr. White-Scott about her plans in New Orleans, Ms. Eglé stated that her desire is to make great changes, statewide by working with the Arc of Greater New Orleans. In response to Ms. Sugarman's question about presumed confidence, she spoke about how confidence can be conveyed through non-verbal communication by people with intellectual disabilities. Ms. Eglé concluded her presentation by stressing the importance of inclusion of people with intellectual disabilities in employment and in the community.

## **Role of the Ex-Officio Members and their Departments**

Chairman Brett called on each ex-officio representative to speak about his/her agency and the role that they would play on the Committee.

### **Alexa Posny**

#### **Assistant Secretary, Office of Special Education and Rehabilitative Services, U.S. Department of Education**

Assistant Secretary Posny shared facts and figures about the role of education in the lives of people with intellectual disabilities and how this role has been amplified in recent years. She stated that every child in this country has a basic right to learn and contribute to society, and having an intellectual disability does not alter that right. She then shared statistics that highlight significant progress for children with intellectual disabilities in their pursuit of an education:

- In 1975, over 1.75 million children with disabilities were excluded from schools and from society; and in 1970, only one in five children with disabilities were educated within the U.S. Schools and many states had laws barring children who had an intellectual disability.
- In 1975, President Gerald Ford signed into law the Education for All Handicapped Children Act. Today, 92 percent of students age 6-21 with intellectual disabilities are educated in regular classrooms for at least some part of the school day. The high standards set for students with ID have led to increased graduation rates.
- As of 2009, 39 percent of students with ID graduate with a regular high school diploma. Six percent receive a diploma of completion, and less than 20 percent of students with ID drop out of high school.
- The percentage of youth with ID who enrolled in any post-secondary school after high school has risen from 8 percent in 1990 to 28 percent in 2005. Approximately 21 percent of these students enroll in two year or community colleges, 20 percent enroll in vocational, business or technical school and 5 percent enroll in a four-year college or university.
- The reauthorization of the Higher Education Act has a new focus placed on students with ID. Institutions of higher education are provided grants to enable them to create or expand high quality inclusive model comprehensive transition and post-secondary programs for students with ID. In 2010, the U.S. Department of Education made 27 grant awards.

Assistant Secretary Posny then described some of the employment successes of students with ID stating that according to 2009 data, transition-age youth with ID achieve employment outcomes

at about the same rate as other transition-age youth with disabilities (52%). She added that when youth with ID receive vocation rehabilitation supports, they are three times more likely to achieve competitive employment with supports than other transition-age youth in the same program.

In closing, Assistant Secretary Posny highlighted some of the goals of the Department of Education, including refining the current systems, policies and practices in order to ensure that all students are educated to the highest possible standard and that they are prepared for jobs in the 21<sup>st</sup> century. She stressed the importance of promoting the numerous ways in which we are more similar than different while respecting each other's differences.

**Margaret Schaefer**  
**Senior Policy Advisor, Office for Civil Rights and Civil Liberties, U.S. Department of Homeland Security**

Ms. Schaefer described how the Office for Civil Rights and Civil Liberties is responsible for monitoring a multitude of civil rights issues, including those that affect people with ID. This office is the lead for an Interagency Coordinating Council on emergency preparedness and people with disabilities, which ensures that the federal government supports the safety and security of people with disabilities throughout its programs and employment practices.

Ms. Schaefer emphasized a major achievement of the Council, "the National Disaster Recovery Framework", a document which contains civil rights considerations for state planners, local planners and people at the community level when drafting recovery plans for their community following a disaster. Principles within the document have already been utilized by Federal Emergency Management Agency (FEMA) in their handling of the recovery following the deepwater oil spill and the more recent tornadoes.

Ms. Schaefer also noted that the Office on Disability Integration and Coordination, within FEMA, advises FEMA on any actions taken within the country that may affect people with disabilities.

**Mary Kay Mauren**  
**Senior Attorney/Advisor, the Equal Employment Opportunity Commission (EEOC)**

Ms. Mauren shared the EEOC Offices help enforce Title VIII of the 1965 Civil Rights Act, which prohibits employment discrimination based on race, color, religion, sex, among other federal laws relating to equality. These offices allow people to discuss their employment situations and decide if they want to file a charge. Within the field of intellectual disabilities, the EEOC enforces Title I of the Americans with Disabilities which prevents the discrimination towards people with disabilities in employment situations. Ms. Mauren described the Congress's decision, in 2008, to broaden the definition of disability to better include individuals with ID, and the regulations being set forth to enforce this broadening. She concluded her presentation by mentioning a fact sheet about employment for people with ID and citing examples of accommodations that may be received at various stages of employment. This information is on EEOC website, [www.eeoc.gov](http://www.eeoc.gov).

**Caffin Gordon**

**Associate Director, Policy and Quality Control Division, Office of Civil Rights, U.S.  
Department of Transportation**

Ms. Gordon highlighted the following initiatives from the handout (included in the resource binder) she provided in the meeting:

- The CARS program promotes the awareness of child seats on the market specifically designed for children with various disabilities.
- Project Action promotes cooperation between the transportation industry and the disability community to increase mobility for people with disabilities.
- The Department of Transportation is involved with the Coordinating Council on Access and Mobility which ensures transportation is provided to individuals with disabilities and low income.

**Dr. Rosaly Correa  
Deputy Director, Office on Disability, U.S. Department of Health and Human Services  
(HHS)**

Dr. Correa presented several initiatives and hallmark reports that summarize some of the work done by the Department of Health and Human Services in the field of intellectual disabilities.

- *Closing the Gap*, released in 2002 by Surgeon General David Satcher, is national blueprint to improve the health of persons with intellectual disabilities.
- The 2005 Call to Action by Surgeon General Carmona focused on the improvement of health and wellness of persons with disabilities, specifically with health care providers' treatment of the entire person, not just the disability.
- The Office of Disability (OD) seeks to improve coordination of existing programs and service systems while ensuring optimal usage of funding. Among its challenges are the lack of a standard of training on disability and the lack of standards for certain medical equipment. The Office on Disability also leads Section 2402 which deals with monitoring home and community-based services and how they are delivered.
- The National Institutes of Health have a number of research centers that focus, specifically, on intellectual and developmental disabilities.
- The Centers for Disease Control and Prevention is working on filling in the gaps in data collection in relation to people with intellectual disabilities.

**William D. Falsey  
Special Assistant to the Director, U.S. Department of the Interior**

Mr. Falsey explained the presence of the U.S. Department of the Interior on the Committee as an employer, as provider of services, and as purveyor of opportunities and experiences for individuals with intellectual disabilities. Ms. Roach elaborated on the role of this Department as provides support to efforts to prevent or minimize the occurrence of Fetal Alcohol Syndrome (FAS) among Native American populations. FAS is considered the number one preventable cause of ID.

**Michelle Aronowitz**

**Deputy General Counsel, Enforcement and Fair Housing, U.S. Department of Housing and Urban Development (HUD)**

Ms. Aronowitz detailed several programs, within HUD, that relate to housing for individuals with intellectual disabilities. The first, the Housing Capacity Building Initiative for Community Living, is partnership collaboration between federal agencies and community service providers to create housing opportunities and facilitate independent living in the community. Another program is Section 8-11 Supportive Housing Program for Persons with Disabilities, which provides grants to nonprofits to finance development of housing for very low-income persons with disabilities and the availability of social services. And, finally, the Multi-Family Housing Service Coordinator Program funds service coordinator to assist persons with disabilities locate and use supportive services provided by community entities.

Ms. Aronowitz also spoke on the enforcement responsibilities of HUD, as this department enforces the Fair Housing Act and Section 504 of the Rehabilitation Act of 1974 which allows people with intellectual disabilities to file complaints if they believe they have been discriminated against in housing and HUD will attempt to remedy the issue.

**Richard Balkus  
Associate Commissioner, Program Development, Office of Retirement and Disability, U.S. Social Security Administration (SSA)**

Mr. Balkus explained the Office of Retirement and Disability is responsible for the disability research and employment policy for the Social Security Administration. This includes support of return to work for beneficiaries under the Supplemental Security Income Program for receiving benefits based on disability or under the Disability Insurance Program. Mr. Balkus also expressed a desire to see the simplification of incentives for the disability insurance program so it is easier for beneficiaries to utilize. He mentioned the SSA's work relating to the transition of youth with disabilities, birth defects, and developmental disabilities, and the return of people with IDs to work.

Dr. Spitalnik interjected that, in the past, the SSA and PCPID have worked collaboratively in the evaluation of children with ID from minority communities, and in assessing their behavioral needs.

The explanation of the ex-officio's departmental contributions to the Committee was followed by a discussion of the development and funding of training programs for professionals that would prepare them to provide services to people with intellectual disabilities, as well as the development of standards for medical equipment. This discussion was in response to the challenges cited in the presentation by Dr. Correa in her introduction to the programs currently run by DHHS.

(Brief Recess)

**Discussion Regarding PCPID 2011-2012 Agenda  
All Members**

Chairman Brett reconvened the meeting with housekeeping notes which included: time management; transportation; and lunch accommodations. He then introduced discussion of the 2011-2012 agenda. The Chair recommended that members keep in mind the timeframe for preparing to the President, as presented earlier by Ms. Lewis and Ms. Roach, and the resources currently available to the Committee. He explained that, if data collection plays a role in the subject matter recommended by a member, it will be that member's duty to collect the data as there is no staff available to do this.

Committee members shared input about the writing and framework of the report. Laverdia Roach explained that there are options available to put the report on the Internet, and publish a limited number of printed copies. She mentioned the past precedent for the recruitment of a writer, and noted that the cost to print fewer hard copies would be significantly less if basic dissemination through the Internet. Ms. Lewis spoke on the current trend of submitting reports electronically to the President and Congress, instead of through printed media. She also stated that, although there would likely be a writer, the majority of the report's content would still need to come from the Committee members.

Dr. Spitalnik suggested that the Committee think about the report in an 18-month framework, with consideration of the 2011 and 2012 report in the framework of a larger mission/goal. This is to help the Committee think broadly, expansively, and constructively as a single unit.

Ms. de Velasquez suggested that members whose interests lie in areas outside of the focus of the 2011 report could take the time to research material for what will be submitted 18 months from now.

Ms. Quirk stated that, based on conversations from the previous day, the history of PCPID portrays people with ID as being disrespected and devalued and that these individuals have expressed their desire to own homes of their own, make their own choices and be included in life in the same way as everyone else. They also wish for a means of communicating their thoughts to the community. Secondly, she stated that the focus of today's Committee discussion appears to be on service providers such as medicine, legal advice, education, etc. Ms. Quirk speculated, therefore, that the 2011 report should address the presumption of confidence, communication issues and, overall, be more conceptual. And, for the 2012 report, the notion of competence and providing everyone with an opportunity to communicate could be its basis with an overlapping focus being the lack of respectful and content-heavy preparation of professionals in providing service to people with ID.

Ms. Sugarman emphasized the importance of respect, knowledge sharing, and community acceptance. She expressed a desire to take a broad sweep across the significance of presumption of competence and balancing the intellectual abilities with the realities of the situation.

Mr. Berns presented the idea of making a descriptive piece on what the world looks like for the people who are not served by the system, or making a comparison of what the situation is like for people who are served versus those who are not. Ms. Roach asked how the Committee would get the data for those individuals who are outside of the system. Mr. Berns recommended starting with a literature review, then trying to bring together information from other sources in a way that can tell a story. He noted that there is a fair amount out there, yet information is piecemeal, and has not been pulled together to make it into a story. Mr. Berns supported Dr.

Spitalnik's idea of thinking of the report in terms of an 18 month framework and developing something in 2011 that is just a step towards the greater piece. In terms of discrete topics, he suggested saying something specific about people waiting for services as well as on those who are not served in the system. He thought the Committee could develop a report focused on the state of self-advocacy in the country and the issue of family support.

Mr. La Mell advocated for the Committee focus to be a little broader, especially under time constraints and with limited resources. He suggested the education has to be beyond our field. He recommended talking to the public, and stressed getting support from them and reaching out to them in their terms realizing what people with intellectual disabilities need. Ms. Lewis commented that, on the autism front, there is a separate Committee specifically focused on autism issues.

Mr. Falsey announced that he would defer to all the other experts on what the substance of the report should be. He agreed with Dr. Spitalnik's point of using the Committee's anniversary as addressing the issues such as communications and use of technology.

Ms. Ramirez stated she is driven by what was heard from self-advocates, and recommended their participation on the Committee. She suggested, if there are initiatives that are in place already, we have some movements that PCPID might tag onto and give more emphasis to, such as community, because that encompasses employment and transportation. Ms. Ramirez offered that is something that we could really focus on.

Ms. Hardiman described her input from perspective managed care, noting that there is a dwindling pool of workers to support people in managed care happening all around the country. She said that she loved the idea of the voice of self-advocates, but felt there are some huge and extreme challenges that she did not know how to incorporate into the report.

Ms. de Velasquez expressed if there is a way to make every targeted recommendation to people who develop disability curriculum that they have to mainstream disability in all their curriculum development; whether lawyers, doctors, or educators to come out with some strong recommendation and implementation having that be a part of something that talks about the right to live independently, linking that to Obama's "Year on Community Living," trying to pick up threads within the Administration, but having something that we do now a piece of something larger that highlights the right to be included meaningfully in the community.

Mr. Boatright hoped the Committee would introduce something new and that is something tangible. He liked Dr. Spitalnik's idea of something, which starts in 2011, which is a precursor to a stronger body of work for 2012, there is a process flow. He was also impressed by Mr. Berns' suggestion of looking outside the system because most of the work that is done looks at the system and the system right now is largely the government-orchestrated system. He suggested exploring what is going on outside the system is worth identifying and bringing forward, leading to the next step. He shared Carol's concern for people who do not communicate in a traditional style, citing the example of what a difference technology can make for people with autism and intellectual disabilities. When equipped his children with an iPad, he saw new talents and behaviors emerge.

Ms. Edelson expressed support for the inclusion of self-advocates. She also noted that employment is a very important theme.

Dr. White-Scott talked about the importance of addressing public service, education, and awareness.

Dr. McKenzie Anderson stated that after she watched the video, *Life in the Shadows*, she decided that the country has made great advancements. She suggested that the Committee might be remiss if it did not recognize the 50 years of advancement with a report to the President as it relates to where we have been, where we are now, where we are going.

Dr. Spitalnik recommended the topic of the full participation of people with intellectual disabilities in their community as the long version of the report. She also talked about the funding challenges for other topic/themes/trends. She encouraged the members to create the blueprint for themselves and raise awareness of what the challenges are

Ms. Wheeler applauded Dr. Spitalnik's idea for bringing it all together. She advised that the goal was to review the challenge list and focus on a few priorities.

Laverdia Roach reminded members that they have an audience of one. She stated the purpose of the report is to inform the President. Mr. Balkus concurred with Laverdia. He stated it is an opportunity to not only speak to the President but the rest of the Administration. He noted that it comes down in terms of identifying it as the challenge and then providing information there that would help get attention to the issue. Mr. Balkus continued it is very important in providing advice in terms of finding a way to get the attention of policy makers, which translates into some type of change.

Mr. La Mell raised the question whether the focus areas are going to be determined by consensus or by vote?

Commissioner Lewis directed the members to go back to their mission as stated in the charter. That is, promoting full participation through the development of advice and recommendations. She encouraged the Chair to determine the approach before determining the focus, and suggested that a decision on process first be made, and what the Committee would like to accomplish for the December 31, 2011 deadline; and then consider process for the end of 2012, and the relationship between the two.

Ms. Quirk recommended framing it as a 50<sup>th</sup> anniversary state of the state for people with intellectual disabilities. She suggested the challenges could become the national priorities that must be addressed which converts to our advice. Then the 2012 report could be the Committee's decision after it has worked together and gotten to know each other, as individuals; then select of those priorities that, as a group, they want to address.

Dr. Spitalnik reminded members that there is a lot of work going on now within DHHS on the long-term care provisions of the Affordable Care Act. She stated that the committee should want to make sure, the money follows the person, not only addresses nursing homes for people who are older but really takes into account the needs of people of all ages with developmental disabilities.

Chairman Brett stated that what the Committee is going to do is two reports: one for the end of this year, much smaller, much more compact, and the longer one would be the 18-month where the Committee will address challenges and recommendations. Chairman Brett asked the members to develop the issues before attempting to create recommendations. Ms. Roach reminded members to advise the Chair about any role that he might take to ensure that the recommendations are addressed.

Mr. Berns asked his fellow members to think of the short-report in terms of the retrospective of the statement of the current -- the current state of affairs and some immediate opportunities. Dr. Spitalnik responded that she would not suggest this approach because it is labor intensive.

A motion to develop a 2011 report that will serve as the basis or the framework for the 2012 report that includes strong recommendations was approved.

### AFTERNOON SESSION

#### *Prospective Focus of 2011 Report to the President*

After receiving permission from the Committee Chair, Dr. Dawn Carlson from the National Institute on Disability and Rehabilitation Research (NIDRR), Department of Education, discussed a 2003 report by the American Association of Intellectual and Developmental Disabilities, called "Keeping the Promise." Dr. Carlson noted that this report provides a great resource surrounding post-secondary education issues. He also mentioned that NIDRR has a large pool of resources of knowledge of databases, and that if Committee members have information needs, or requests, he would be happy to help the members to gain access to these resources. Dr. Carlson suggested that members concerned with including valid suggestions, should look at that report.

Committee members engaged in an extensive discussion about their transportation, to the hotel and airport, scheduling of the next Committee meeting, FACA requirements for scheduling conference calls, and public meetings.

Chairman Brett returned members' attention back to the Report to the President. He summarized the previous conversations, explaining how one section of the shorter 2011 report would contain a segment on history, in addition to including a section on current issues and challenges. The Chair also suggested that the Committee dedicate a portion of the historical section to Eunice Shriver. This portion could be taken from excerpts of Dr. Spitalnik's article, with her permission.

Chairman Brett agreed with Dr. Spitalnik's suggestion to have a short history in the first report that would reference to a larger one in the second report.

Dr. Spitalnik suggested using the original President's Panel Report as a starting point, as it provides the beginning of federal funding and because the field of intellectual disabilities has changed drastically in the nearly 50 years since that report was published. She also stressed the importance of expressing clearly the themes of both the smaller and larger reports which she stated was essential to determining challenges. Dr. Spitalnik also suggested that the purpose of

this report would be to promote the full community integration of people with intellectual disabilities. Ms. Quirk agreed with this suggestion and added that this purpose could be used as a bridge between reports.

Mr. Berns suggested two elements for the first report: one being a summary of how the state of the state is now, and one being short term or immediately realizable recommendations that would lead into the more in-depth, complicated recommendations of the second report. He noted that the former element should be supported by research from different sources that help to answer the question of how we are doing. The recommendations for the first report are those that are important for the President to hear this year instead of waiting for the following report.

Ms. Hardiman suggested that the Committee use something from the self-advocates in *“Keeping the Promise Report,”* as a staging area to measure the state of the state. Ms. Ramirez agreed with this and suggested that it be used in place of a whole history, which could be added to the longer second report. In response to Mr. Boatrights’ question on what would come in the later report, Ms. Hardiman offered using data from Braddock, Lakin and other sources to support the data taken from the self-advocates in the first report.

Ms. Hardiman shared that ADD currently has a funding opportunity announcement related to the collection of family support data, and the distinction between individuals who are living in a family home and the services and supports that they receive in-home versus supports to the family. She mentioned that when looking at the gathered data by David Braddock, one could conclude that every individual who lives in a family home and who is receiving supports as family support is counted. Dr. Spitalnik added that the metric under the research conducted by Charlie Lakin on family support includes factors that families might not say was directly family support (training that is open to families).

Mr. Berns expressed opinion that report should speak to where people are living, are employed, and whether they are being included in school. Mr. Boatright responded that he wishes to see something very specific and uniquely tangible adding. “There is a lot of work out there that speaks to the global state of today and which often reiterates the same point over and over.” Chairman Brett expressed concern that often professionals in the field do not know where the data is, and who will get access to it.

Dr. Spitalnik recommended considering a larger economic circumstance, which often has a tremendous impact on services by different States. She added that some of the movement to both managed care for health care and also managed long term care, through Affordable Care Act, is worthy of exploring. Chairman Brett reminded Committee members that the self-advocate presenter (Jill Eglé) encouraged them to take a look at employment for individuals with intellectual disabilities.

Ms. Quirk suggested that the Committee first look at employment, community living, education and then consider health care and some of the information about the providers, the preparation of the educators, lawyers, doctors and other providers, in the larger report. She said that it would be great to write about the 50<sup>th</sup> anniversary of the Committee and then rally around some of the self-advocate points. Dr. White-Scott suggested that Committee members look at it from a retrospective of what are some of the things that were asked before, what has been accomplished, and if any of that still is pertinent or also ties into some of the self-advocates' work around

employment to conceptualize the short-term report. Ms. Edelson agreed and added that the short-term report should start with the voice of self-advocates.

Mr. Berns admonished that the Committee should be careful not to overplay putting out the voice of self-advocates when it holds just one self-advocate member. Ms. de Velasquez replied that we do not have to say we are speaking for self-advocates. The state has an obligation in promoting the active role of people with disabilities. In the case of “helping develop peer support”, it would be people with intellectual disabilities in developing policy, monitoring the implementation of that policy, and delivering services that they are receiving.

Ms. Wheeler mentioned that some post-secondary programs are related to the employment issues, because they give an opportunity for young people to continue to get the skills that they need. She added that the topic of independent living has also had an impact on residences. With regard to the post-secondary education, Commissioner Lewis informed the members that ADD has funded one of its university centers with a project called “Think College.” The ThinkCollege.net website has listed approximately 150 programs designed for students with intellectual disabilities. The Commissioner added that the challenge is about how do we bring students with intellectual disabilities into higher education and have their needs met. She added, the question is, what would the Committee be adding to the current conversation around post-secondary options, she said.

Mr. Falsey asked if there is a consensus about how Committee measures the state of the state, and if there are metrics or indicators that are acceptable. Mr. Boatright stated that using metrics could be a good starting point. On the issue of the post-secondary analysis, he suggested that the report span across developmental levels and levels of significance of disabilities to address what different programs are available. Ms. Quirk suggested developing a four-part report. The introduction referencing the 50<sup>th</sup> anniversary, Eunice Kennedy Shriver’s contribution, and the state of initial reports. The second section can include progress of where individuals with intellectual disabilities live, go to school, and how they spend their time as adults (work). The third section can cover the current hot spots. For instance, we talked about technology as a vehicle for communication; skills and attitude of service providers. The last section should include recommendations and progress.

Chairman Brett encouraged members to make a decision before the end of the day.

Ms. Hardiman emphasized the importance of full participation of individuals with intellectual disabilities in the community. She also mentioned the isolation and loneliness experienced by people with intellectual disabilities.

Ms. Edelson asked if conversation about housing, employment, and post-secondary education is geared towards individuals post age-21. Ms. Sugarman responded that to her personally, it is about prenatal care, birth, as postsecondary education to her does not solely mean education in the formal sense of college.

Mr. Berns asked if the Committee could come up with three to five trends that are changing the face of life for people with intellectual and developmental disabilities, and talk about the history and purpose of each trend in the report. For example, people are living in their own homes and apartments, we can give a little history around how housing and residential options have evolved in this field and why that is important and then talk what is known about how people live today,

he suggested. He also stated that it would be helpful if PCPID staff could take on the task of compiling into a single document perhaps a list of all the recommendations from the past reports and indicate whether or not they were implemented.

Mr. Berns recommended the formation of a small volunteer group, in preparation of the next meeting, to gather the Committee members' ideas and propose an outline for what this report should introduce. Chairman Brett asked for volunteers and four members agreed to complete this task (Burns, McKenzie Anderson, Spitalnik, and Quirk). Dr. Spitalnik suggested sending a framework to each member asking them to identify the most important trends. Ms. de Velasquez asked if it is possible to streamline the process through a survey monkey. Commissioner Lewis responded that this is not a possible option, because it would be considered being a vote.

The volunteer group will develop the framework questionnaire and share that with Laverdia by Friday, June 24, 2011 for dissemination among the members. Upon receipt of the three priority trends from all members, PCPID staff will organize them in a single template. Mr. Berns defined a "trend" as developments in the field that are changing life for people with intellectual and developmental disabilities.

Ms. Quirk asked Laverdia Roach if the Committee members could receive a copy of the notes taken by PCPID staff. Laverdia replied that members could have a copy of the informal notes taken by PCPID staff prior to preparation of the meeting minutes from the official meeting transcript. She added that PCPD staff will receive the transcript in 10 business days and start converting it into minutes, immediately. Ms. Quirk then asked the Chairman if there is someone to chair the workgroup. Chairman Brett took a prerogative and made the appointment of Dr. Spitalnik and Mr. Berns as the co-chairs of the workgroup. They both responded positively.

Ms. de Velasquez suggested that after compiling all the recommendations from previous Reports to the President, the single document be shared with various ex officio agencies and national organizations for identification of implementation.

Committee members decided to hold two conference calls; one for July 19, 2011 and one August 17, 2011. They also suggested convening a face-to-face meeting before the end of Fiscal Year 2011 (September 23-24, 2011 or September 26-27, 2011).

Chairman Brett thanked all the members for their support, and added that he values the members' knowledge and passion in the field of Intellectual Disabilities.

Chairman Brett had a motion to adjourn the meeting.

Meeting adjourned.

Action items:

***PCPID staff:***

- 1) Share the informal notes taken during the meeting with the Committee members.
- 2) Convert the meeting transcript into minutes.
- 3) Schedule two meeting, via conference call, for July 19, 2011 and August 16, 2011.
- 4) Schedule a face-to-face meeting for September 23-24, 2011 or September 26-27, 2011.
- 5) Share with the Committee members contact information of the ACF officials responsible for Ethics, Financial Reports and Member Certification, and Travel.
- 6) Receive the electronic Copy of the report by AAIDD, *Keeping the Promise*, from Dr. Dawn Carlson, DoED, and forward that to the Committee members.
- 7) Create a template for similar themes/trends/topics discussed during the meeting and receive feedback from the members prior to the next meeting.
- 8) Compile all the recommendations included in the Reports to the President (1967-2009) in one single document.

***Committee Members:***

- 1) Submit their travel invoices and receipts to the PCPID Budget Officer within five business days after the meeting.
- 2) Receive, from PCPID staff, and read the Report by AAIDD: *Keeping the Promise*.

***Co-Chairs and the Volunteer Workgroup:***

Develop a feedback template to solicit Committee members' preferred themes, trends, and topics by Friday, June 24, 2011.

**Themes/Trends/Topics of the 2011 PCPID Report to the President by PCPID Members:**

- Full community participation of people with intellectual disabilities
- State of self-advocacy
- Needs of people with intellectual and developmental disabilities of all ages
- Autism
- Reaching for public support to realize what people with intellectual disabilities need
- Issues of family support
- Employment
- Transportation
- Public awareness and the role of the public in supporting employment of people with intellectual disabilities
- Residential support
- Independent living
- Housing
- Individuals who are not receiving residential supports through Medicaid
- Number of individuals living in residential settings six and under, nationally
- The Affordable Care Act (ACA) and long term care
- Data Collection on the status of people “Outside the System”
- Challenges related to limited State resources
- Money following persons with intellectual disabilities
- Post-Secondary Education (PSE)
- Pell grants and work-study programs
- Educational challenges and quality standards

- Transition (as a broad topic) support for people post age-21
- Targeted recommendations to curriculum developers
- Technology/Assistive Technology
- Communication/applicability for people who do not communicate in traditional style
- Direct support professionals
- Skills and attitudes of direct support professionals
- Managed-care for individuals with intellectual disabilities
- Road blocks that supporters may create in the way of individuals with intellectual disabilities
- The impact of loneliness



President's Committee for People with Intellectual Disabilities

## PCPID Meeting Agenda June 16-17, 2011

U.S. Department of Health and Human Services  
The Hubert H. Humphrey Building (HHH Bldg.)  
200 Independence Avenue, S.W.  
Conference Room 505-A  
Washington, D.C. 20201

**Day One:** Thursday, June 16, 2011

- 9:30 a.m. – 9:35 a.m.                    *Greetings, Call to Order, and Introduction of  
David A. Hansell, ACF Acting Assistant Secretary*  
Sharon Lewis, Commissioner  
Administration on Developmental Disabilities  
Designated Federal Official (DFO)  
President's Committee for People with Intellectual Disabilities
- 9:35 a.m. – 9:40 a.m.                    *Welcoming Remarks and Introduction of Swearing-in Official*  
David A. Hansell  
Acting Assistant Secretary for Children and Families  
Administration for Children and Families

- 9:40 a.m. – 10:30 a.m.      *Swearing-in Ceremony for Appointees to PCPID and Photo Op*  
Kareem Dale  
Special Assistant to the President for Disability Policy
- 10:30 a.m. – 10:45 a.m.      **REFRESHMENT BREAK**
- 10:45 a.m. – 11:00 a.m.      *Opening Remarks and Approval of Agenda*  
James T. Brett  
Chair  
President’s Committee for People with Intellectual Disabilities
- 11:00 a.m. – 12:00 Noon      *Self-Introductions*  
Chair  
Members and Ex officio Representatives
- 12:00 Noon – 1:00 p.m.      **LUNCH (on your own)**

**PCPID Committee Meeting Draft Agenda  
Continued**

- 1:00 p.m. – 2:55 p.m.      **BRIEFINGS AND ORIENTATION**
- 1:00 p.m. – 1:15 p.m.      **Role of White House Liaison**  
Presenter:      Mike McCauley  
White House Liaison  
Office of the Secretary  
U.S. Department of Health and Human Services
- 1:15 p.m. – 1: 20 p.m.      **Speaker-Committee Dialogue**
- 1:20 p.m. – 1:35 p.m.      *PCPID Procedures Manual*  
Presenter:      Laverdia Taylor Roach  
President’s Committee for  
People with Intellectual Disabilities  
Administration for Children and Families
- 1:35 p.m. – 1: 40 p.m.      **Speaker-Committee Dialogue**
- 1:40 p.m. – 1:55 p.m.      **Federal Advisory Committee Act (FACA)**  
Presenter:      Patricia Mantoan  
Senior Attorney  
General Law Division  
Office of the General Counsel  
U.S. Department of Health and Human Services

- 1:55 p.m. – 2:00 p.m. **Speaker-Committee Dialogue**
- 2:00 p.m. – 2:15 p.m. **REFRESHMENT BREAK**
- 2:15 p.m. – 2:30 p.m. **Ethics**  
 Presenter: Naomi Miske  
 Associate Counsel for Ethics Education  
 Office of the General Counsel  
 U.S. Department of Health and Human Services
- 2:30 p.m. – 2:35 p.m. **Speaker-Committee Dialogue**
- 2:35 p.m. – 2:50 p.m. **Travel Procedures**  
 Presenter: Gail Bowles  
 Manager  
 Division of Support Services  
 Administration for Children and Families  
 U.S. Department of Health and Human Services
- 2:50 p.m. – 2:55 p.m. **Speaker-Committee Dialogue**
- PCPID Committee Meeting Draft Agenda  
 Continued**
- 2:55 p.m. – 3:30 p.m. ***Overview of PCPID Alignment within HHS, Administration  
 Agenda on Disability, and Wrap-up***  
 Sharon Lewis  
 Commissioner
- 3:30 p.m. **RECESS**  
  
*See Transportation Details Below*

**Transportation Details:**

- 8:15 a.m. First van pick-up to transport Committee members from L'Enfant Plaza Hotel to the Hubert H. Humphrey Building
- 8:45 a.m. Second van pick-up to transport Committee members from L'Enfant Plaza Hotel to the Hubert H. Humphrey Building
- 3:30 p.m. First van pick-up to transport Committee members from the Hubert H. Humphrey Building to the L'Enfant Plaza Hotel.
- 4:00 p.m. Second van pick-up to transport Committee members from the Hubert H. Humphrey Building to the L'Enfant Plaza Hotel.

**PCPID Committee Meeting Draft Agenda  
Continued**

**U.S. Department of Health and Human Services  
The Hubert H. Humphrey Building (HHH Bldg.)  
200 Independence Avenue, S.W.  
Conference Room 505-A  
Washington, D.C. 20201**

**Day Two: Friday, June 17, 2011**

- 9:00 a.m. – 9:10 a.m. *Call to Order*  
James T. Brett  
Chair
- 9:10 a.m. – 9:30 a.m. *History: "Life in the Shadows" Video*
- 9:30 a.m. – 9:50 a.m. *Self-Advocacy: Why is it Important?*  
Jill Eglé  
Co Executive Director  
The Arc of Northern Virginia
- 9:50 a.m. – 10:30 a.m. *Ex officio Members' Agency Updates (3 minutes, each agency)*  
Designated Ex officio Representatives

- U.S. Department of Justice – Mark L. Gross
- U.S. Department of the Interior – William D. Falsey
- U.S. Department of Commerce – Suzan J. Aramaki
- U.S. Department of Labor – Kathy Martinez
- U.S. Department of Health and Human Service – Henry Claypool
- U.S. Department of Housing and Urban Development – Michelle Aronowitz
- U.S. Department of Transportation – Camille M. Hazeur
- U.S. Education Department – Alexa Posny
- U. S. Department of Homeland Security – Margaret Schaefer
- Corporation for National and Community Service – Jewel Bazilio-Bellegarde
- Social Security Administration – Richard Balkus
- Equal Employment Opportunity Commission – Mary Kay Mauren
- National Council on Disability – Gary Blumenthal

10:30 a.m. – 10:45 a.m.      ***REFRESHMENT BREAK***

**PCPID Committee Meeting Draft Agenda  
Continued**

10:45 – 12:00      ***Discussion Regarding PCPID 2011-2012 Agenda***  
All

12:00 Noon – 1:00 p.m.      ***LUNCH (on your own)***

1:00 p.m. – 2:00 p.m.      ***Prospective Focus of 2011 Report to the President***  
All

2:00 p.m. – 3:00 p.m.      ***Work Sessions on 2011 Report to the President***  
Workgroup Chairs/Members

3:00 p.m. – 3:15 p.m.      ***REFRESHMENT BREAK***

3:15 p.m. – 3:45 p.m.      ***Work Sessions on Action Items***  
Workgroup Chairs/Members

3:45 p.m. – 4:00 p.m.      ***Summary of Priorities***

James T. Brett  
Chair

4:00 p.m.

***ADJOURNMENT***

***See Transportation Details Below***

**Transportation Details:**

- 8:15 a.m. First van pick-up to transport Committee members from L'Enfant Plaza Hotel to the Hubert H. Humphrey Building
- 8:45 a.m. Second van pick-up to transport Committee members from L'Enfant Plaza Hotel to the Hubert H. Humphrey Building
- 4:00 p.m. Van pick-up to transport Committee members from the Hubert H. Humphrey Building to the Airport.