



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

~Minutes~

Swearing-in Ceremony and Full Committee Meeting
September 3-5, 2014

DAY ONE (September 3, 2014)

Citizen Members

Julie Ann Petty, Chair
Susan Axelrod
Peter Berns
Jack Martin Brandt
James T. Brett
Kenneth Capone
Micah Fialka-Feldman
Dan Habib
Zachary W. Holler

Stacey Milbern
Lisa M. Pugh
Susana Ramirez
Michelle Reynolds
Deborah M. Spitalnik, PhD
Ricardo T. Thornton, Sr.
Elizabeth Weintraub
Sheryl White-Scott, M.D.
Betty Williams

Ex officio Members and Representatives

Mark L. Gross/Jennifer Eichhorn
Representing the Honorable Loretta E.
Lynch, Attorney General, U.S.
Department of Justice

Sharon Lewis
Representing the Honorable Sylvia
Burwell, Secretary, U.S. Department of
Health and Human Services

Suzan J. Aramaki
Representing the Honorable Penny
Pritzker, Secretary, U.S. Department of
Commerce

Michelle Aronowitz
Representing the Honorable Julián
Castro, Secretary, U.S. Department of
Housing and Urban Development

Kathy Martinez (Assistant Secretary) and
Serena Lowe
Representing the Honorable Thomas E.
Perez, Secretary, U.S. Department of
Labor

Yvette Rivera
Representing the Honorable Anthony
Foxx, Secretary, U.S. Department of
Transportation

Sue Swenson (Deputy Assistant Secretary)
Representing the Honorable Arne Duncan,
Secretary, U.S. Department of Education

Brian Parsons (via telephone)
Representing the Honorable Jeh Johnson,
Secretary, U.S. Department of Homeland
Security

Stephanie Enyart
Representing the Honorable Wendy
Spencer, CEO, Corporation for National
and Community

Leola Brooks/ Deborah Engler
Representing the Honorable Carolyn W.
Colvin, Acting Commissioner, U.S. Social
Security Administration

Mary Kay Mauren
Representing the Honorable Jacqueline A.
Berrien, Chair, Equal Employment
Opportunity Commission

Gary Blumenthal
Representing the Honorable Jeff Rosen,
Chair, National Council on Disability

Special Guests

Kathy Greenlee
Assistant Secretary on Aging and
Administrator, Administration for
Community Living (ACL)

Taryn Mackenzie Williams
Associate Director, the White House
Office of Public Engagement

Micki Edehlsohn
Emeritus PCPID Member

Patricia Mantoan
Attorney, HHS Office of the General
Counsel

Steve Hagy
Director, ACL Office of Budget and
Finance

Natalie Pojman
The White House Liaison

Katherine A. Hess
HHS Ethics Counsel

Kelly Selesnick
HHS-PCPID Ethics Counsel

Annette McKenzie Anderson
Emeritus PCPID Member

Bradley Walters
The White House Liaison

The Administration on Intellectual and Developmental Disabilities (AIDD)-PCPID Staff

Aaron Bishop
AIDD Commissioner and PCPID DFO
Madjid "MJ" Karimi, PhD
PCPID Team Lead
Sheila Whittaker
PCPID Program Assistant

Carrie Ann Johnston
Executive Assistant
Erica Key
Administrative Assistant
Judy Minor
Staff Support Assistant

Meeting Proceedings

Greetings, Call to Order, and Introduction of Special Guests

Aaron Bishop, Commissioner and Designated Federal Official (DFO)

The September 3-5, 2014 meeting of the President's Committee for People with Intellectual Disabilities was called to order by Aaron Bishop, Commissioner of the Administration on Intellectual and Developmental Disabilities and PCPID Designated Federal Official. He welcomed the new Appointees, their families, Ex officio members' representatives, and special guests to PCPID. Commissioner Bishop provided a description of the purpose and history of the Committee from its inception as President Kennedy's Panel on Mental Retardation in 1961. He referred to the Committee Appointees as "the living and breathing rendition of a vision that President Kennedy and Eunice Kennedy Shriver had." Commissioner Bishop detailed some of the major topics considered by the PCPID members in the past; including, but not limited to, employment, self-advocacy, and managed long-term services and support. He then presented the Associate Director of the White House Office of Public Engagement, Ms. Taryn Mackenzie Williams to offer welcoming remarks.

Welcoming Remarks and Introduction of Swearing-in Official

Taryn Mackenzie Williams

Associate Director, the White House Office of Public Engagement

Associate Director Williams welcomed the meeting participants, on behalf of the White House, and congratulated new appointees to the Committee. She shared with the Appointees that the Administration for Community Living (ACL) is more than a place that runs programs or carries out the law or give out funds; it exists to serve people with disabilities. Ms. Williams added that the PCPID also exists to transform lives and noted with no doubts, "the collective impact of Committee members' efforts can change the world for people with disabilities." She then presented Ms. Kathy Greenlee, Assistant Secretary and Administrator of ACL, to lead the swearing-in ceremony.

Swearing-In Ceremony

Kathy Greenlee, Officiant

Ms. Greenlee welcomed the new Appointees to PCPID, on behalf of Secretary Sylvia Burwell, and described several recent ACL achievements that seek to benefit people with Intellectual and Developmental Disabilities (IDD). She expressed the desire to ensure that the community living service and support needs for both the aging and disability populations are addressed at ACL. Assistant Secretary Greenlee added that the ACL is stronger when its values are driven by self-advocates, families, and advocates. She also acknowledged the support that PCPID will get from the thirteen (13) Ex officio member representatives on the Committee. Assistant Secretary Greenlee, then, proceeded to lead the new Appointees in repeating the *Oath of Office*.

(Brief Recess)

Opening Remarks and Approval of Agenda

Julie Ann Petty, Chair

Ms. Petty, PCPID Chairwoman, officially called the meeting to order. She shared with the members her pride, honor, and excitement to be the first individual with IDD to be named Chairperson of PCPID. Ms. Petty added that, in the next two days, members will have the opportunity to discuss and vote on suggested topic(s) for the PCPID annual Report to the President. She also called for the approval of the meeting agenda, which was unanimously approved by the PCPID members. Chairwoman Julie Petty expressed that as a Chairperson, she would like to create an atmosphere in which all members feel free to speak their minds.

Self-Introductions

Chair, Members, and Ex officio Representatives

Chairwoman Petty introduced herself. She also asked PCPID members to give self-introductions that included their background in the field of IDD and their current work.

(Mid-Morning Recess and Dismissal of the Federal Members)

AFTERNOON SESSION

Chairwoman Petty opened the afternoon session by announcing the agenda, which included presentation by the leadership of the HHS Office of the White House Liaison as well as a number of trainings (i.e., Federal Advisory Committee Act, Ethics, PCPID Procedure Manual, and Travel/Budget). She stated that this was an opportunity to meet key policymakers who play a major role in daily operation of the Administration. Ms. Petty then introduced the White House Liaisons from the Office of the Secretary of Health and Human Services, Mr. Bradley Wolters and Ms. Natalie Pojman, both of whom gave updates on their roles and responsibilities.

Role of White House Liaison

Bradley Wolters and Natalie Pojman, The White House Liaison

Mr. Wolters and Ms. Pojman welcomed the Committee on behalf of the President and the Secretary of Health and Human Services. They expressed appreciation to the members for their willingness to serve the Administration and for their patience in the appointments vetting process. Mr. Wolters and Ms. Pojman added that the role of advisory Committees is very important to the Department, because this is the only way under the law, that HHS can take and receive official input from experts outside the federal government. They then invited questions from the PCPID members.

Dr. Deborah Spitalnik suggested that the Office of the White House Liaison realizes the importance of continuity of services, especially with preparing the annual Report to the President, during the vetting process. Mr. Wolters responded that he and his colleagues have been working on new ideas to ensure the continuity of the Committee's appointments and reappointments.

PCPID Procedures Manual

Madjid “MJ” Karimi, PhD, PCPID Team Lead

Chairwoman Petty introduced Dr. Karimi who serves the Committee as the Team Lead. Dr. Karimi provided an extensive overview of PCPID procedures. He mentioned that the purpose of the presentation was to provide information and guidance regarding the purpose, structure, membership, staffing, and function of the Committee.

“MJ” 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 IDD, and to improve the quality of their daily lives. He reminded members that although their expected tenure is two years, they serve at the pleasure of the President.

Dr. Karimi 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 and the DFO. He shared with the members that one of their responsibilities 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. Dr. Karimi 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. Then, to select from those focus areas, topic(s) that they believe will make the greatest impact.

After summarizing the review process for the report, Dr. Karimi invited questions and further group discussions.

Ms. Liz Weintraub asked about the length of the PCPID Executive Order (E.O.). Dr. Karimi responded that the current E.O. will be expired on September 30, 2015. Ms. Weintraub asked if the PCPID E.O. is expected to be signed by the President in 2015. Chairwoman Petty added that “the last time (in 2013) there was a debate whether or not the E.O. would be signed by the President,” but “we don’t need to be worried about that right now.”

Ms. Weintraub asked if the Committee has enough time and resources to complete the report in a year. Commissioner Bishop responded that the timeframe to complete the annual Report to the President is a year from September 2014. He added that the AIDD has some funding available to hire a contractor; should there be a need for assistance in writing the report.

Mr. Jim Brett suggested sending an invitation to the contractor(s) to participate in the meetings. Chairwoman Petty replied that the decision has been made, at this point, by the ACL leadership to prepare and write the report in-house by the PCPID members and staff. Mr. Jack Brandt asked how many recommendations from the last report, on Managed Long-term Services and Support, were implemented and what the outcome was. Dr. Karimi responded that it was premature for knowing the outcome of a report with fifteen (15) recommendations that was submitted to the President less than a year ago. Dr. Spitalnik added that, overtime, the intent of PCPID has been to raise issues and educate the general public because of the nature of the reports and the way they have been prepared and designed.

Ms. Susana Ramirez asked two questions: (1) what happens in the process of completion of the report if some of the members exit out in May of 2015; and (2) how long does it take to seek approval for the final report from the other Departments of government (i.e., Ex officio agencies). Dr. Karimi reminded the members that, as the leadership of the Office of White House Liaison explained earlier, there will be a mechanism in place to appoint or reappoint members to the Committee on time. He also added that in order for the Committee to allocate adequate time to the Ex officio agencies for the vetting process, the final report should be close to completion by May of 2015.

Ms. Susan Axelrod asked “how the membership of PCPID is—who is invited?” Dr. Karimi responded that the appointments have been directly made by the President. Commissioner Bishop added that at time individuals are recommended (sometimes through the political appointees) however, some people may be ruled out during the vetting process.

Federal Advisory Committee Act (FACA)

Patricia Mantoan

Attorney, Office of the General Counsel

Ms. Patricia “Patty” 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 highlighted some of the statutory requirements of FACA and explained that the burden for compliance rests with the agency, not with the Committee members. She added that the PCPID is created by a Presidential E.O., which lays out the functions of the Committee, and that an in-house Charter explains the Committee’s roles and responsibilities.

“Patty” Mantoan described 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 Federal Officials without the approval of the full Committee. She explained that the Committee’s annual reports are filed with the Library of Congress to allow researchers to have access to past reports. She closed her presentation by stressing the importance of compliance with FACA requirements, and then invited questions.

Mr. Peter Berns asked if the transcripts of the PCPID meetings would be available to the general public. Ms. Mantoan replied that under FACA, transcripts are available upon request— so a member of the public does not have to file a Freedom of Information Act request, but instead can request under the FACA, at cost of duplication.

Mr. Dan Habib asked if the notes from the working groups should also be available to the general public. “Patty” responded, when working with workgroups/subcommittees, it is not legally required to make the meeting minutes available to the public. Mr. Zach Holler asked about the final report recommendations and what happens to them, if “indeed implemented.” Ms. Mantoan replied that the recommendations will first go the HHS and then the Secretary will

transmit them to the White House. It is, however, difficult for the HHS to state how many recommendations will be implemented immediately.

Mr. Jim Brett added that one of the previous Committees developed an idea called long-term savings plan for people with IDD. He added that, as the Committee meets today, the Congress of the United States will be voting on the ABLE (Achieving a Better Life Experience) Act, which is the exact wording from the PCPID 2004 Report to the President.

Ethics Training

Catherine A. Hess and Kelly Selesnick
Ethics Counsel

Ms. Catherine Hess began her presentation by introducing her colleague from the HHS Ethics Division, Ms. Kelly Selesnick, who is assigned to work with the PCPID members.

Ms. Hess defined the meaning of a Special Government Employee (SGE) and noted that SGEs have relaxed ethics rules compared to fulltime Federal employees. SGEs are expected to work fewer than 130 days in a period of 365 consecutive days. Ms. Hess asked the members if this was an issue for any of them. The members responded “no.” She, then, encouraged the members to always refer to the comprehensive Departmental ethics rules and regulations shared with them prior to the training and take their questions to Ms. Selesnick and Commissioner Bishop.

Ms. Hess 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. Mr. Holler asked about a situation in which a PCPID member might receive Medicaid waiver for medical care, should the person recues himself/herself from any discussions about the Medicaid? Ms. Selenick responded “No, this is a federal benefit and not a financial interest for purpose of the criminal conflict of interest statue.”

Ms. Hess pointed out that the ethics rules are codified in a criminal statute and that violation of the rules could come with fines and possibly prison terms, and that 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 the Administration for Community Living anytime they believe that they may have conflicts of interest or “may be invited to give expert witness testimony as a PCPID member.” Ms. Hess continued by asking the Committee members if there have been instances in which they performed certain duties that might be considered specific party matters. Members responded that there have been such instances.

Mr. Brandt asked in the case of members who belong to University Centers, should the university be precluded from applying for the federal grants? Ms. Selenick responded that this is a specific party matter—if a general policy or program would affect all universities and not one affiliated university individually, it would be fine to apply for federal grants. Note that if one is on the Board of Trustees of an affiliated university, a waiver needs to be requested. Mr. Habib asked about a situation in which one refers to his or her position at PCPID while writing a grant. Ms. Selesnick encouraged the members to check with her, in advance, to analyze each situation. Ms. Lisa Pugh asked if she could use her PCPID title on regular e-mails. Ms. Selenick

responded that the situation in which one may think they have received the e-mail from PCPID must be avoided.

Mr. Ricardo Thornton asked about the government rules and regulations revolving around gifts. Ms. Selesnick replied that if you are offered a gift because of your position with the government, please feel free to contact her at: Kelly.Selenick@hhs.gov. Several exceptions are associated with gift rules—one of them being accepting a gift that is \$20 or less.

Ms. Hess concluded her presentation by highlighting the Hatch Act rules, which restrict the ability of federal employees to engage in partisan political activities.

Travel Procedures

Steve Hagy, ACL Office of Budget and Finance Director

Chairwoman Petty presented the next speaker, Mr. Steve Hagy, Director of the ACL Office of Budget and Finance. Mr. Hagy notified members that they will not receive individual travel cards. Instead, the ACL-PCPID staff will be responsible for making travel arrangements, answering any questions that come up, making changes if something happens at the last minute, which prevents their participation in a meeting, and processing reimbursements.

Mr. Hagy added that the staff points of contact (POC) that members should predominantly rely on are Ms. Sheila Whittaker and Ms. Betty Jeter-Hicks. The ACL has an e-Gov travel service, called GovTrip, which enables staff to reserve Committee members' lodging, airfare, rail, rental car, etc. Mr. Hagy noted that the members will be expected to follow all of the travel rules that affect federal employees, which means they should look for travel that is most advantageous to the federal government. There are, however, limits in regard to what expenses can be incurred. For example, hotel rates must be within the government rate that governs each city; mileage for personal automobile is 56 cents per mile; and travel should be made in coach unless there is a documented medical necessity. An important rule of thumb is to keep receipts for everything, including meals and incidental expenses (M&IE), which is normally referred to as per diem.

Mr. Hagy concluded his presentation by promising to provide a list of both the general travel rules and the contact information for the ACL POCs.

Overview of Meeting Goals and Objectives

Julie Petty, Chair

Aaron Bishop, Commissioner and DFO

Chairwoman Petty opened the session by sharing with the members that most of the September 3-5, 2014 PCPID Meeting Agenda was her idea to ensure that members were given enough time to discuss their concerns. Ms. Stacey Milbern asked if the roles and responsibilities of the workgroups could be explained. The Chairwoman responded that she has made the decision to divide the full Committee into three groups; the workgroups will be responsible to meet, conduct a discussion about the potential topics/themes for the report and, finally, report out to the entire Committee.

Ms. Pugh asked if the work of PCPID relates back to the strategic planning of the AIDD and its self-advocacy summit. Commissioner Bishop replied that can be a reference point; however, PCPID is an independent body and can decide to focus on something completely different.

Mr. Habib suggested establishing some Committee norms or expectations. He provided examples as: members' punctuality to start and finish the sessions on time; and decision-making based on the majority rules. The next ten (10) minutes were spent discussing "Committee norms or expectations" related to Mr. Habib's suggestions:

- Listen to each other (Dr. Spitalnik)
- Respect all opinions around the table (Mr. Thornton)
- Each Committee member should speak at least once (Dr. White-Scott)
- Stay true to the charge of the PCPID (Ms. Pugh)
- Use accessible language (Ms. Milbern)
- Allow individuals time to respond (Mr. Holler)

Mr. Brandt asked the Chairwoman and the Commissioner if they could provide more information regarding the structure of the workgroups. Commissioner Bishop responded that the full Committee will be broken up into three groups of at least ten (10) members. Within each group, there should be one person who will take the lead (moderator) in guiding the group and its discussions and, at the end of the day, report out. Group members will have discussions about what is important, what areas they think that the Committee should focus on and, within that context, come up with specific ideas regarding what should be the topic of the report.

Mr. Berns asked if the work group can get the chance to meet face-to-face again, or solely should rely on communication through e-mails and phone. Commissioner Bishop responded that PCPID is budgeted for two face-to-face meetings and two conference calls for the next fiscal year (FY15). So, some of the work will be done by e-mails and phone, but the Committee has the ability to meet face-to-face again. Mr. Brett requested that the experts in the chosen topic of the Report to the President be invited to the PCPID meetings/conference calls. Chairwoman Petty responded positively to this request and added that the length of the next face-to-face meeting will be two days, and conference calls may be short or up to two hours.

Ms. Pugh asked about the Ex officio updates scheduled for the following day and if they will provide the Committee with "unique perspectives." Dr. Karimi responded that the PCPID Ex officio member representatives are asked to provide two recent initiatives that their agencies are embarking upon in the context of policy. Their perspectives may trigger fresh ideas regarding the topic that PCPID report should be focused on in 2015.

Commissioner Bishop announced the membership scrolls have arrived from the State Department, and gave members the choice to pick them up in person or request future deliveries.

(Afternoon Recess)

DAY TWO (September 4, 2014)

Call to Order and Introduction of Video Clips on Thasya and Self-Advocacy

Julie Ann Petty, Chair

The September 4, 2014 meeting was called to order by Chairwoman Petty who welcomed the Committee members. Meeting participants viewed a clip from the documentary film, “Thasya,” produced by PCPID member, Dan Habib. Following a brief discussion of the clip, Mr. Blumenthal thanked Dan and expressed belief that to follow Thasya over the years would be a remarkable asset in helping families who are approaching the “terror of post 22.” Mr. Habib responded that he has recently been in contact with Thasya’s teacher and been apprised that she is doing great. Thasya is in middle-school now and regrettably she is spending most of her time in self-contained classrooms. According to Dan, fifty-six (56) percent of students with ID spend their entire day in self-contained environments.

Why Self-Advocacy is Important. What is the Future of Self- Advocacy?

PCPID Members

Following the review of the video clip “Self-Advocacy,” PCPID members discussed the future of the self-advocacy in the United States. Ms. Pugh expressed belief that parents need to see these sorts of videos and conversations much earlier in their children’s lives, to observe how independent and self-determined people could be. Some of early intervention models are so medically oriented that parents might not think about what the future can be for their children. Mr. Thornton believes that self-advocacy is important because it helps people to set goals and achieve those goals.

Mr. Fialka-Feldman shared with the members that self-advocacy should be taught at an early age. Ms. River mentioned that self-advocacy is also about mentoring, seeking mentorship, and networking. Mr. Blumenthal agreed and added that self-advocacy should be seen as one leading light that helps to build a wide coalition. Ms. Reynolds added that self-advocacy organizations can also help individuals with disabilities gain skill sets through inclusion as well as family-setting expectations. Ms. Milbern noted that self-advocacy is all about the vision on how to make the world a better place. Mr. Brett concluded the discussion by pointing out that many young people on the video had a tag, saying “I voted or I will vote” and “that’s how their voice is heard in the community.”

Ex officio Members’ Agency: Discuss the Two most Important Initiatives for People with Intellectual Disabilities and their Families

Chairwoman Petty called on each ex officio representative to speak about the two most important recent initiatives for people with ID and their families in their Departments.

Mary Kay Mauren

Senior Attorney Advisor, Equal Employment Opportunity Commission (EEOC)

Ms. Mauren began her presentation by sharing that the EEOC offices enforce Title I of the Americans with Disabilities Act (ADA), which prohibits employment discrimination against people with disabilities, and also enforce the Rehabilitation Act in terms of its enforcement of nondiscrimination with the federal employees. She described the EEOC training program on

reasonable accommodations obligations and its outreach to federal agencies to develop strategies for employing more people with disabilities. Ms. Mauren added that the EEOC has recently published, in the Federal Register, an advance notice of proposed rulemaking to receive comments from the public about what is working regarding employment in the federal government for people with disabilities. She concluded her presentation by pointing out that there will be reports specifically for people with IDD driven from this advance notice.

Sue Swenson

Deputy Assistant Secretary, U.S. Department of Education (DoED)

Deputy Assistant Secretary Swenson shared some facts about the role of the DoED in the lives of people with IDD. One initiative at the Department is currently undertaking is regarding the disproportionality of the over identification of students of color as having particular kinds of disabilities. There are geographic patterns to this disproportionality in the United States. The Department is also spending time in managing waivers (related to No Child Left behind Act of 2001, & Elementary and Secondary Education Act) and research how many students with disabilities are included in the standardized tests, both the statewide tests and the National Assessment of Educational Progress. Initial analysis is showing that states that have increased the numbers of students with disabilities who are included in the testing have also increased their testing outcomes.

Ms. Swenson outlined other Departmental investments such as PBIS.org on positive behavior interventions and support and SWIFT, which is intended to ensure that schools are inclusive not only for the students with disabilities, but also for poor students and English language learners in an organic way. In closing, Ms. Swenson referred to the Workforce Innovation and Opportunity Act (WIOA) of 2014, and the new opportunities of transition/reorganization, and writing new regulations on competitive integrated employment.

Serena Lowe for Assistant Secretary Kathy Martinez

Senior Policy Adviser, U.S. Department of Labor (DOL)

Ms. Serena Lowe detailed several programs within the DOL. The Office of Disability Employment Policy recently received authorization under the WIOA. A number of teams are, therefore, looking at areas of youth school-to-work transition, employer agreement, and overall employment support of people with disabilities. The Employment First State Leadership mentoring program was also launched in 2012 to align policies, funding streams, and public systems to prioritize integrated employment as a preferred outcome of “day employment services.” In addition, the DOL entered into agreement with the AIDD to collaborate and coordinate its efforts in the field to promote employment of, and holistic wraparound supports, for people with IDD. Ms. Lowe added that another success is the Rhode Island settlement agreement on developing an interagency memorandum of understanding on how the system works to transition over 2000 people into community-based integrated employment over the next ten (10) years.

Ms. Lowe continued her presentation by talking about a self-determination piece that brings more requests from states for family advocacy support. The DOL has a pool of national subject-matter experts that assist with developing family coalitions. Ms. Lowe also talked about the final ruling around 503, which sets a suggestion to all employers of federal contractors of a seven (7) percent hiring of people with disabilities. Finally, an E.O. was issued by the President in

February, 2014 that requires all new federal contracts that are service-oriented to pay a minimum wage at \$10.10 per hour as the regulations will be issued soon.

Mark Gross

Deputy Chief, U.S. Department of Justice (DOJ)

Deputy Chief Mark Gross explained that the DOJ is working to expand the “Olmstead” Act into the area of employment, get rid of sheltered workshops, and encourage employment in the community in an integrated setting as well as in the area of education. He shared that the DOJ has also started an initiative to help people with ID on the issues of school bullying and harassment, which are tremendous problems for individuals with Autism and Asperger’s syndrome.

Stephanie Enyart

Disability and Inclusion Advisor, the Corporation for National and Community Service (CNCS)

Ms. Enyart explained that CNCS’ charge is to increase the number of people with disabilities being served, by providing funds to grantees to successfully run their projects. CNCS has redone its technical assistance materials in terms of e-courses, and revamped its entire web infrastructure. The agency also has begun relationships with the ACL, in a Memorandum of Understanding, to be able to further strategize in getting people with IDD in larger numbers in different service corps.

Gary Blumenthal

Council Member, the National Council on Disability (NCD)

Mr. Blumenthal explained that the NCD currently has nine (9) members, with five (5) who are appointed by the President under the WIOA Act, and additional four (4) members who will be appointed by the Speaker of the House, the Senate Majority Leader, the Senate Minority Leaders, and the House Minority Leader. Much of the NCD’s work will be cross-disability focused and the agency will reach out to other federal partners as well. The NCD has published several publications with specific recommendations offered to sister agencies, and cabinet-level Departments within the federal government. Mr. Blumenthal pointed that the NCD was commissioned to produce a report on deinstitutionalization to address and identify significant activities that took place before in closing the institutions. Also, the NCD website offers a great policy toolkit for state decision makers with myths about the costs associated with closing the institutions. Mr. Blumenthal concluded his presentation by mentioning the NCD’s Medicaid Managed Care Project on long-term services and support to PCPID members.

The Department of the Interior (DOI) [not present]

Deputy Assistant Secretary Swenson mentioned that the DoED works with DOI on a highly successful Project SEARCH program, which is a transition-to-work, skills training program for students with disabilities in their last year of high school.

Michelle Aronowitz

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

Deputy General Counsel Michelle Aronowitz detailed the responsibilities of the HUD in areas of enforcement and fair housing with examples from actual scenarios. She added that HUD gave almost \$98 million to thirteen (13) states in discretionary grants. These states won the money to provide rental assistance for extremely low-income individuals with disabilities, including persons with IDD who were transitioning out of institutions. These monies were also designed to assist with state housing and/or subsidize housing. Ms. Aronowitz pointed out that HUD issued the “Olmstead” guidance, last year that explained housing should be provided and must be provided in the most integrated setting appropriate to the needs of the persons with disabilities. The Section 811 program was reauthorized in 2010 to give more flexibility to the states to implement the program in the most integrated setting consistent with “Olmstead.” With regard to Section 8, Ms. Aronowitz mentioned that it is a program that provides individual housing vouchers to persons, not just with disabilities, but to low-income persons who need housing.

Deborah Engler on Behalf of Leola Brooks

Senior Advisor, U.S. Social Security Administration (SSA)

Ms. Engler addressed research in the area of youth with IDD and transition. The SSA has five (5) different sites offering benefits counseling and employment support to youth receiving Supplemental Security Income (SSI). Ms. Engler noted that the SSA, DOL, DoED, and HHS have partnered on the Promise Project, which promotes readiness of minors and SSI program—SSA will evaluate the program. She added that the Work Incentive Planning and Assistance (WIPAs) provides counseling, which helps beneficiaries with understanding complicated rules on earnings and employment. The WIPAs will be tasked with targeting SSI for youth in transition, ages 14 to 25, including outreach programs to parents, teachers, schools and community centers. Finally, the SSA is partnering with the Office of Personnel Management (OPM) in creating a shared list of people with disabilities for employment purposes.

Yvette Rivera

Associate Director, U.S. Department of Transportation (DOT)

Ms. Rivera started her presentation by saying that transportation is the key to independent living; the ability to go to workplace, healthcare, and places of worships. The DOT is working with Congress to reauthorize legislation, the Grow America Proposal, which includes a 70% in accessible transit. Ms. Rivera noted that her agency is working on the Project Action, the National Technical Assistance Center, and the Federal Transit Administration in advancing best practices in travel training. She concluded that under the ADA, complementary Para-transit is required (referring to the new authorization), DOT is seeking to address gaps in public transportation system that does not serve people with disabilities, appropriately.

Sharon Lewis

Principal Deputy Administrator, U.S. Department of Health and Human Services (HHS)

Principal Deputy Administrator Sharon Lewis pointed out that at HHS, the primary and continuing priority is the implementation of the Affordable Care Act (ACA). She added that understanding how people with ID and their families have been affected by the ACA is a question for the Committee to ponder. The Administration is committed to ensuring the promise (e.g., discrimination based on a preexisting condition, access to affordable and accessible coverage) of the ACA, which is a huge focus of the work of HHS. The ACA started with policy reform issues, and now there is a need to figure out how health services should be delivered.

Principal Deputy Administrator Lewis further noted that, as the delivery system reform shapes itself, there remains an open question in terms of what does that mean for long-term services and support. Because the ADA and Olmstead, desire of individuals to live in the community, and in part because of changes to the definitions of Home and Community-Based Settings (HCBS), there are many opportunities “to move the ball down the road.” Ms. Lewis added that although policymakers talk about employment, they do not normally talk about the rest of people’s time, or what that means in the context of supporting families. Approximately, 80-85% of people with IDD live with their families. The policymakers cannot devote into a binary conversation where employment is good and anything else people with IDD do during the day is less important.

Principal Deputy Administrator concluded her presentation by sharing that states have five (5) years (referring to the changes in HCBS definition) to move their system along, and this is going to be an important federal-state conversation moving forward.

Brian Parsons (via telephone)

Senior Policy Advisor, U.S. Department of Homeland Security (DHS)

Mr. Parsons began his presentation by pointing out the work of DHS after a disaster and its interactions with people with IDD. The DHS has passed a new policy directive to strengthen compliance with the Rehabilitation Act and reinforce key principles related to program accessibility and physical accessibility and effective communication with people with IDD. Part of this policy directive involves self-evaluation of agency programs and activities from disability perspective. Mr. Parsons added that the DHS is in the process of developing policies on recovering from disasters or traveling and security related issues for people with disabilities.

Mr. Habib asked how is the decrease of hiring people with disabilities within the federal government, from 1.07 percent in 2002 to 0.9 percent in 2014, explained. Ms. Lowe from DOL responded that there is some up-to-date data out of the OPM, which the PCPID members should rely on. Mr. Berns noted that the OPM current data shows no growth at all in employment by the federal government of people with ID. This is due to the fact that most federal jobs are currently being contracted out. Ms. Lewis added that in fiscal year 2012 (FY12), non-seasonal full time permanent new hires with disabilities, including 30% or more disabled veterans, totaled 16,000, representing an increase from 14.65% in FY2011 to 16.31% in FY 12. Needless to say, in FY12, people with disabilities were hired at the highest percentage in 32 years. The HHS, EEOC, DOL, and DoED, SSA have been engaged with the OPM about the E.O. to ensure the federal hiring initiatives moves forward.

Mr. Berns asked the representative of HUD to describe her agency’s position on disability-specific housing. Ms. Aronowitz replied that the Fair Housing Act does not speak to disability-specific housing, but section 504 and regulations around it explain that housing must be in the most integrated setting.

(Afternoon Recess)

Introduction of Discussion Groups

Julie Ann Petty, Chair

Chairwoman Petty called for the continuation of the session. She informed Committee members that they will be divided into three workgroups, and encouraged them to use flipcharts to capture their ideas during their formal discussions. Chairwoman Petty asked the workgroup to answer the following questions:

- 1) What is important to people with ID and their families?
- 2) If you are asked to write an award-winning report to the President in 2015, what would that be?

The structure of the workgroups is listed below:

Julie Ann Petty, Chair

Workgroup # 1	Workgroup # 2	Workgroup # 3
<ul style="list-style-type: none"> • Michelle Aronowitz (HUD) • Susan Axelrod • Jim Brett • Darren Cruzan/Sue Settles (Not Present) • Zach Holler • Kathy Martinez/Serena Lowe (DOL) • Stacey Milbern • Deborah Spitalnik • Sue Swenson (ED) • Ricardo Thornton 	<ul style="list-style-type: none"> • Peter Berns • Gary Blumenthal (NCD) • Ken Capone • Mark Gross (DOJ) • Dan Habib • Brian Parsons (DHS) • Shelli Reynolds • Yvette Rivera (DOT) • Wendy Spencer (CNCS) • Liz Weintraub 	<ul style="list-style-type: none"> • Suzan Aramaki (DOC) • Leola Brooks (SSA) • Jack Martin Brandt • Micah Fialka-Feldman • Sharon Lewis (HHS) • Mary Kay Mauren (EEOC) • Lisa Pugh • Susana Ramirez • Betty Williams • Sheryl White-Scott
Staff Assistant: Carrie Ann Johnston	Staff Assistant: Erica Key	Staff Assistant: Dr. MJ Karimi

Each workgroup’s notes on the flipcharts during their formal discussions are shown below:

WORKGROUP 1

- Medical services/training — where the people are
- ID/DD aging population
- Police interacting

Data information: A call for more...

The Affordable Care Act (ACA) Information Technology – Disability Tech.

Community Development: Does community have what is needed...

- Housing access
- Transportation
- Safety
- Making connections

Adult/Aging

- Employment
- Health (much better for children currently)
- Aging families
- People whom US services
- Health Disparities
 - Access
 - Conditions
 - Lack of Information

Health Care...

- ACA
- Transition to adult life
- Disparities

WORKGROUP 2

Bill of Rights for People with Intellectual Disabilities

- Income security/ Freedom from poverty
- Meaningful, individualized education
- Lives free from violence and abuse
- The right to affordable integrated, accessible housing (quality housing)
- Freedom to live and go where you want
- Access to health care over the lifespan (health and wellness opportunities)
- Autonomous life: The right to personal identity
- A right to make one's own decision
- Access to technology
- Barrier-free community/Universal Design

WORKGROUP 3

Future -Thinking Report: Drills down to a concrete and appropriate framework (timing + policy)

Award-winning Report!

Theme: Good Life for Next Generation of People with Intellectual Disabilities and Their Families.

- Role of the technology in ensuring a good life
- What makes a good life?
- Technology as an equalizer across lifespan
- The role of technology in culture change: Start a revolution
- Technology is emerging and mainstream (Google cars; Google glass, Apps; new ways to monitor health, smart homes)

Audience: Family members of people with intellectual disabilities all ages, and policymakers who are looking for solutions.

Timing: Time to plant seeds of ideas (election cycle):

- Promote public and private partnerships (role of universities)
- Promote self-efficacy and interdependence
- Making the point that investments mean less reliance on service system

ID Lifespan Gaps: Where inclusion/classroom membership falls apart;
How system is inflexible to allow for true social connect
We are not prepared... (Quote Statement from Chart)

Technology needs to be part of public policy solution (going forward – entitlement).

Full Committee Discussion and Group Report

Working groups

The Committee reconvened after the Workgroups' "discussion" sessions.

Workgroup #1:

Ms. Stacey Milbern and Dr. Deborah Spitalnik reported out. Ms. Milbern outlined the workgroup's discussion into three domains: 1) community development (e.g., housing, safe neighborhood, and transportation); 2) transitioning into adulthood; and 3) healthcare. Dr. Spitalnik continued by saying that discussion in the area of healthcare involved the healthcare disparities for people with ID and other disabilities, lack of training for healthcare professionals and, finally, coverage on healthcare.

Workgroup #1 would like to ensure that the implementation of the ACA addresses people with disabilities not only in terms of long-term care, but also individualized healthcare. This workgroup was concerned that the education process of healthcare professionals does not address the fact that there will be a growing crisis as access to care is improved under insurance; and that there won't be enough providers to address the healthcare needs of the U.S. population. The

ACA holds the responsibility of information technology as well as the needs for comprehensive data and information.

Workgroup #2:

Ms. Liz Weintraub and Ms. “Shelli” Reynolds reported out. Ms. Weintraub stated that workgroup #2 discussed the future of people with IDD. The Workgroup came up with a “Bill of Rights” for People with IDD. Group members talked about income security, and freedom from the poverty in the context of careers rather than jobs. The discussions also included the meaningful individualized education, violence and abuse-free environments, affordable and integrated housing, and access to health care. Other areas in the Bill of Rights included the right to personal identity, access to technology, barrier-free communities, and universal design.

Ms. Reynolds noted that there is need for a big “push in the field.” She pointed out that the ADA and IDEA are fundamental pushes in the field, which one can look back on and notice different achievements on, but the field of IDD lacks something to push advocates and self-advocates to the next level. The Workgroup talked about the Bill of Rights for People with IDD to recognize the many integrated life areas that are important. Workgroup members expressed hope that the suggested “Bill of Rights” be used by the federal system for different programs.

Mr. Berns informed the Members that the United Nations Convention on the Rights of People with Disabilities is currently in session. He added that, perhaps, the idea addressed by this Workgroup presents an opportunity to articulate some principles for people with disabilities across America. Dr. Spitalnik expressed concern that this proposal felt like a backward step; even though, the contents of it are what the members will agree on. Ms. Reynolds responded that there are social assumptions in the U.S. about people with disabilities that will continue to carry on. This workgroup is proposing a change to the social paradigm about individuals with disabilities.

Workgroup #3:

Ms. Lisa Pugh and Mr. Micah Fialka-Feldman reported the discussions of Workgroup #3. Ms. Pugh noted that the suggested topic/theme by Workgroup # 3 is centered on the idea of a good life for the next generation of people with ID and their families. This is an issue with which everyone is struggling. States are struggling with this as they look at how to implement the integrated settings rule. Workgroup members asked the following questions: “What happens in people’s days when they are not working?” and “What does this full context of life and membership look like for people with ID?” Group members concluded that “technology” ensures a good life for people with ID and their families.

Mr. Fialka-Feldman stated that a good life to self-advocates is having a job, going to college, and building relationships with others. Ms. Pugh reported that the Workgroup also discussed the role of technology as somewhat of an equalizer across the life span for people. Some of the older technologies such as “Dragon Speak” and “Dynavox” are currently being replaced by emerging technologies, and “we are on the cusp of a revolution.”

The Workgroup also discussed the role of technology in culture change. Technology can provide social connections for people, help them maintain their health, live in their homes longer, and become independent or interdependent. Micah pointed out that technology plays a

role in social relationships across life span, and “we noticed how it helped to bridge the gap in school for young people with disabilities.” Ms. Pugh added that the aging community also benefits from technology as it develops small circles of support for folks so that people can check in on them in a timely manner. For instance, the Smart Home Technology can help to monitor things like climate control in the home as well as medication and things that help individuals to maintain their independence.

The Workgroup discussed the direct care workforce crisis, aging baby boomers, and the explosion of people that are going to need support. Members asked: “Is there a role for technology and a way to look at different pieces of technology to address these crises?” The policymakers will be ripe for hearing some of these different ideas and solutions (i.e., public-private partnerships). The iPads are replacing the use of *Dynavox* technology and different non-service-oriented solutions to transportation. These investments can ultimately mean less reliance on the service system. The Workgroup proposes that the next PCPID Report to the President identify certain gaps that exist in the service system. Some other overarching issues are: poverty and cultural diversity.

Chairwoman Petty thanked the presenters and informed the Committee that the next step is to come up with a consensus on the theme of the PCPID 2015 Report to the President. Mr. Blumenthal asked if PCPID will receive support from a contractor, specifically hired to write the report. Commissioner Bishop replied that it depends on the direction that the Committee will take and what will be chosen as the theme of the Report.

Ms. Swenson suggested not to pick just one topic, but rather to write about a topic that has list of key recommendations. Ms. Weintraub asked that PCPID staff, Dr. “MJ” Karimi, share a synopsis of the discussions by the workgroups before the final decisions were made on Friday, September 5, 2014. Chairwoman Petty responded positively to this request and called for the afternoon recess.

(Afternoon Recess—Second Day)

DAY THREE (September 5, 2014)

Call to Order and Recognition of Former Committee Members: Annie Forts and T.J. Monroe
Julie Ann Petty, Chair

The September 5, 2014 meeting was called to order by Chairwoman Petty who welcomed the PCPID members back. The Chair started the meeting by recognizing two former PCPID Committee members, Ms. Annie Forts and Mr. T.J. Monroe, who served the Committee as citizen members in 1990s. Chairwoman Petty and Commissioner Bishop signed the awards to Ms. Forts and Mr. Monroe and appreciation letters to them for being the first self-advocates serving the Committee. They asked the members if they knew Annie and T.J., and if so, was a story or special moment that they wanted to share with the current PCPID members. Mr. Blumenthal shared that at one point the members were invited to the White House to meet with President Clinton and Annie had some promotional materials related to “Up Syndrome (as

opposed t down Syndrome) Campaign” that she was directing and raising funds for. The President saw her “Up Syndrome” button and was very much taken by the idea. Other special stories related to Annie and T.J. were communicated to the members by Drs. Spitalnik and White-Scott.

Discussions on the Final Topic of the Report to the President

PCPID Members

Commissioner Bishop started the session by noting, “Today is a very important day for the Committee” in the sense that members will “stamp their legacy” by going to set forth the topic for the 2015 Report to the President. He stated that the work of PCPID is about the Committee in collective whole. The Commissioner added that the Committee work is also about respecting diversity. When voting for the topic, “We have to be thinking about the mom in Pierre, South Dakota; the young child with autism living in Baton Rouge, Louisiana; and individuals in Tucson, Arizona.” Commissioner Bishop concluded his remarks by encouraging Committee members to consider the following three points: 1) the Committee’s **audience**; 2) **timing** (between now and 2016); and 3) the **impact** of the report.

Ms. Axelrod thanked the Commissioner for his comments and pointed out that some of her experiences have been with her own daughter and peers of hers and people she has know through her living arrangement. She expressed belief that most amazing comments have come out of PCPID self-advocates during the meeting. She shared with the members that her daughter, as a self-advocate, could not sit at such setting and encourage the members to keep her and many others like her in mind when making the final decision on the topic of the Report to the President.

Ms. Rivera agreed and added that the Committee also needs to consider people with IDD who are English learners. Mr. Habib pointed out that he would like to see a report that is a catalyst for significant change within the private sector and public/private partnerships. Mr. Berns mentioned that he would like the report to be read by the platform committee for the candidates for President in 2016 as well as candidates for offices across the country; whether they are state legislative or congressional offices and/or the media. Ms. Pugh added that the distribution and exposure of the report may deserve the work of a certain subcommittee. Mr. Brandt pointed out that the report should be relevant to people with disabilities, if the Committee is aiming to have various audiences.

Mr. Brett expressed belief that almost 51% of the recommendations in the last Report to the President (2012) were implemented. Dr. Karimi shared with the members that 51% of all the PCPID recommendations from its inception in 1967 to 2009 were implemented by the federal agencies. Mr. Ken Capone noted that the impact of the Report should be to better the lives of people with ID and break down the barriers to make this happen. Mr. Blumenthal suggested that the members also consider presenting the materials/recommendations of the Report face-to-face to different audiences. Commissioner Bishop agreed that the overall audience of the Report to the President is everyone. He added that there are some critical features regarding the timing of the Report (2016 election) that needs to be discussed. The Report also has to be approved by the thirteen (13) federal agencies that are represented on the Committee—and that may take some time.

Mr. Holler pointed out that, although the sole audience of the Report is the President of the United States, the Committee Members as special government employees are accountable to the general population. Deputy Assistant Secretary Swenson said that the more policy recommendations are made at the regulatory level, the longer the clearance process will take. Mr. Berns suggested that the PCPID staff prepare a timetable, between now and September 2015, for the completion of the Report to the President. Mr. Blumenthal expressed belief that the clearance process is not an actual term that is applicable here as much as the fact-checking. Ms. Axelrod asked if the PCPID staff ever fields calls from the White House regarding suggested topic. Commissioner Bishop explained that some of the decisions are because of the regulations that come down within agencies that provide the Committee with indications of what are the initiatives of the Congress and the White House. Dr. Spitalnik shared with the members that next summer will be the 25th anniversary of the ADA, which may create some openings for visibility and ensuring that the concerns of people with ID are addressed.

Ms. Milbern asked what timetable the Committee needs to agree on for the preparation of the Report. Chairwoman Petty answered possibly summer of 2015. Ms Ramirez brought to the Committee's attention that the tenure of some members will end in May of 2015, so the preparation of a decent report should be done prior to this time.

Chairwoman Petty said that she has asked Ms. "Sheli" Reynolds to find some commonalities in the notes taken from workgroup discussion the day before and report them out. Ms. Reynolds started with some of the key words that were standing out in the notes. Those words are: the right to dream, secure future, increase expectations, no limitations, upward mobility, enviable life, opportunities, independence, full citizenship, life experience, and typical life from birth. Ms., Reynolds continued by saying that the only word that did not come across in the notes was the concept of meaningful relationship building. The most repeated words were regarding affordable and accessible housing. The other thing that resonated across all of the notes was the concept of future, whether future in transition age or related to aging.

Ms. Milbern asked "Sheli" to summarize the top four common words in the work groups' notes. Ms. Reynolds responded that the words clustered more around poverty, expectations, experiences, and opportunity for full citizenship. Mr. Berns suggested that in preparing the recommendations on the Report, members use the opportunity to describe the progress and the work still needs to be done in the field and invite audiences to take on "the challenge of getting it done." Ms. Swenson suggested that the fairness of the Administration and its efforts to lift everyone needs to be recognized. Mr. Holler recommended use of the domino theory; to pick a particular problem to start with—"and other barriers will then go down with it."

Mr. Habib expressed belief that technology is a part of almost every minute of one's day, and a huge gatekeeper to access membership and participation in the society. "We have a long way to go to make voting truly accessible for people with disabilities." He added that, technology in schools and access to transportation and self-driving cars will be game-changers for many. In addition, there is a gap in Medicaid reimbursement for critical technology that Medicaid, itself, may not see as critical technology but people with disabilities may do. There is also a great opportunity to find technology that allows elderly to live independently. Finally, with regard to jobs, entrepreneurship and micro-businesses and microloan can have tremendous impact on the lives of people with disabilities.

Dr. Spitalnik noted that there is a structure for the Report that is emerging. For instance, Peter

Berns suggested the introduction (i.e., progress has been done, but there is a lot to be done). Then, Lisa Pugh talked about the private partnerships, and “Sheli” provided the identifying words for vision of what people with ID hope in life.

Ms. Rivera suggested looking at technology on a global scale and addressing poverty and accessibility of information in the Report. Ms. Stephanie Enyart added that one other area would be class issue and rural/urban divide. Chairwoman Petty expressed belief that the themes of the Report on technology are coming together with poverty being the main theme and different culture/classes and access being other selected themes.

Mr. Berns suggested that PCPID staff propose a framework for the Report. He also added that the philanthropic community should also be part of the audiences that the Committee identified earlier. For instance, one of the recommendations to the President should be on convening of the private sector, foundations, and ask them to make commitment toward the White House disability agenda. Mr. Brett suggested that perhaps the recommendation be geared towards the role of technology and health disparities. Mr. Habib suggested that “perhaps technology should become a thread” in the Report and the other three issues center around poverty, education, and health disparities.

Chairwoman Petty summarized the discussions as: the **introduction section** of the Report will identify where we have been as society, the progress we made over the years, and include the global perspectives such as full citizenship rights, poverty and socioeconomic status (SES), race, religion, and sexuality. The next section would be a **vision (self-advocacy, family, community, private sector and philanthropic perspectives)**, which talks about what the Committee is aspiring for, what is the future out there, and what type of lives do people with ID want to have. And then, **policy** and what is the vision for policy. Chairwoman Petty asked if the Committee would like to focus on **technology as an overriding area** that includes **education, health disparities, and poverty**; or if the Committee wishes to have technology as a theme in the third section of the report. Commissioner Bishop reiterated that this means that technology is one major theme and poverty, health disparities, and education can be seen through the lens of technology.

Deputy Assistant Secretary Swenson shared with the members that there are three kinds of technology that are important to people with disabilities: 1) assistive technology; 2) communications technology; and 3) management technology. Dr. White-Scott added that physicians, nowadays, are using telemedicine—for example, they can examine a patient 300 miles away, listen to his/her heart rate, lungs, run a diagnosis, and train with residents and trainees at the same time.

Mr. Berns expressed that if the Committee focuses around technology as an overarching principle, it will lose the opportunity to breathe new life into the movement in the field. This opportunity should not be missed in 2016 and in the midst of an election cycle. Mr. Berns added that he believes that the Report should have many recommendations on different topics that workgroups collected and “Sheli” reported on earlier.

Mr. Habib talked about the usefulness of the structure of the Report that was proposed by the Committee. Chairwoman Petty agreed that technology is not the end, but a means to achieve the vision (self-advocacy, family, community, private sector and philanthropic perspectives). Mr.

Habib further suggested that Chairwoman Petty gather a quick straw poll of the room on using technology as a framing element for the 2015 Report to the President.

Voting on the Final Topic of the Report to the President

PCPID Members

Chairwoman Petty asked the members if they agree on the “introduction” and the “vision” sections as two parts of the Report. A quorum of members raised their hands to agree with this suggestion. Next, the third section of the Report be on technology and include areas of poverty, education, and health disparities. The next question that members were asked to vote on was: Do you agree to have technology as the overarching theme of the report? A majority of PCPID members agreed with this suggestion. So, the decision was made to write the PCPID 2015 Report to the President on **Technology** as an overarching topic.

Mr. Berns did not agree with the Committee’s decision and posed a question to the Committee members on what they think about the moral outrage around 85% of people with ID being currently unemployed. Or where is the moral outrage around Ethan Saylor, an individual with IDD, who was killed by the cops in Fredrick, Maryland. Chairwoman Petty responded that she feels that moral outrage as well as she is passionate about certain topic(s), but PCPID members must decide on a topic, collectively.

The PCPID members asked Chairwoman Petty and Commissioner Bishop to invite experts in the field of Technology to the next face-to-face of the Committee. They both agreed. Mr. Habib suggested that PCPID staff sends out an e-mail, asking the members about the focus areas that they would like to be included in the report.

Chairwoman Julie Petty made the motion to adjourn. Liz Weintraub seconded the motion. The meeting was adjourned.

ACTION ITEMS:

PCPID Members

1. Submit all the receipts related to their travels to Washington, D.C. for the meeting to the ACL-AIDD Budget Office by **Friday, September 12, 2014.** (Completed)
2. Recommended presenters, with particular expertise in the field of Technology, to speak to the Committee at the next face-to-face meeting. **(PCPID staff will send out an e-mail to request by Friday, October 31, 2014)**

PCPID Staff

1. Prepare the minutes of the September 3-5, 2014 Committee Meeting by **Friday, October 10, 2014.**
2. Provide a list of general travel rules as well as information for the point of contact at AIDD-PCPID by **Friday, September 12, 2014.** (Completed)
3. Share the correspondence from the OPM with regards to statistics on employment of people with IDD within the federal government by **Friday, September 12, 2014.** (Completed—E-mail was sent out by Ms. Sharon Lewis)
4. Share with the full Committee a synopsis of the discussions/notes by each workgroup before **Friday, September 5, 2014.** (Completed)
5. Prepare a timetable for the completion of the Report to the President by **Friday, October 31, 2014.** (In Progress)
6. Propose a framework for the Report by **Friday, October 31, 2014.** (In Progress)
7. Request the members to recommend presenters in the field of **Technology** for the next PCPID face-to-face meeting by **Friday, October 31, 2014.** (In Progress)