



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

~Minutes~

Swearing-in Ceremony

August 09, 2012

11:30 a.m. – 1:00 p.m., EST

PCPID Re-Appointees

Peter H. Bell
Jack Martin Brandt
Micki Edelson
Ann Hardiman
Alison A. Hillman de Velasquez
Carl M. LaMell

Julie Ann Petty
Lauren Potter
Lillian Sugarman
Carol Wheeler
Sheryl White-Scott, M.D.

Special Guest (Ethics Trainer)

Katherine A. Hess, HHS Ethics Counsel

AIDD-PCPID Staff

Sharon Lewis, AIDD Commissioner
Laverdia Taylor Roach, Senior Advisor
Madjid "MJ" Karimi, Program Analyst
Sheila Whittaker, Program Assistant

Swearing-In Ceremony

Sharon Lewis, Officiant

Commissioner Lewis welcomed the re-appointees to the Committee and thanked them for their patience during the vetting process. She then proceeded to lead the re-appointees in repeating the *Oath of Office*.

Following the swearing-in process, Commissioner Lewis shared with the members that they are scheduled to receive their ethics training by Ms. Katherine A. Hess, Ethics Counsel, Office of the General Counsel, U.S. Department of Health and Human Services. She noted that after completing the ethics training, the Committee will reconvene at 1:00 p.m.

Ethics Training

Katherine A. Hess, Ethics Counsel

Ms. Hess began by defining a Special Government Employee (SGE) and noting 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.”

Ms. Hess encouraged members to always refer to the comprehensive Departmental ethics rules and regulations shared with them prior to the training. 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. Hess pointed out 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 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 Administration for Community Living (ACL) ethics officials (Mr. Edwin Walker, *Designated Ethics Counselor*, and Ms. Erin Long, *Ethics Coordinator*) anytime they believe that they may have conflicts of interest. Ms. Hess continued by asking the Committee members if there have been instances in which they performed certain duties that might be considered specific particular matters. Peter Bell responded that he has some involvements in reviewing grant proposals that are funded through the organization by which he is employed. Ms. Hess suggested that in such instances, Mr. Bell should talk to the HHS-Administration for Community Living Ethics Counselors to avoid any possible criminal conflicts of interest.

Ms. Hess further noted that the term "political activity" means doing something in active support of or opposition to a political party, a candidate for partisan political office (e.g., President, senator, representative, state or local legislature or office), or a partisan political group. She added that the Hatch Act limits certain political activities of Federal employees both on and off duty. Ms. Hess finalized her presentation by admonishing Committee members that violations of the Hatch Act may result in disciplinary action, up to and including removal.



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

Full Committee Meeting

August 09, 2012

1:00 p.m. – 2:30 p.m., EST

~Minutes~

Participants

Citizen and Ex officio Members and Representatives

James T. Brett, Chair	Carol Wheeler
Annette Anderson, Ph.D.	Sheryl White-Scott, M.D.
Peter Bell	Mark Gross (US Department of Justice)
Clay Boatright	Yvette Rivera (US Department of Transportation)
Jack Martin Brandt	Dawn Carlson, Ph.D. (US Department of Education)
Micki Edelson	Serena Lowe (US Department of Labor)
Ann Hardiman	Brian Parsons (US Department of Homeland Security)
Alison A. Hillman de Velasquez	Leola Brooks (US Social Security Administration)
Julie Ann Petty	Mary Kay Mauren (Equal Employment Opportunity Commission)
Lauren Potter	
Carol Quirk	
Susana Ramirez	
Deborah M. Spitalnik, Ph.D.	
Lillian Sugarman	
Liz Weintraub	

Public Participant(s)

Robin Sinkhorn

ADD-PCPID Staff

Sharon Lewis, Commissioner	Madjid "MJ" Karimi, Program Analyst
Jamie Kendall, Deputy Commissioner Laverdia	Sheila Whittaker, Program Assistant
Taylor Roach, Senior Advisor	

Summary of Proceedings

The Meeting began with a roll call by the Conference Call Operator. Brian Parsons, US Department of Homeland Security, listened in for Margaret Schaefer and Serena Lowe, US Department of Labor, listened in for Assistant Secretary Kathy Martinez.

Greetings, Call to Order, and Presentation of Chairman

Sharon Lewis, AIDD Commissioner, PCPID Designated Federal Official (DFO)

Sharon Lewis, PCPID DFO, started by thanking the members with their patience through the reappointments process. She noted that in this meeting, decisions regarding the Committee's focus on the 2012 Report to the President, and scheduling a face-to-face Committee meeting will be made. She, then, called the meeting to order and turned the meeting over to Chairman James Brett.

Welcoming Remarks and Meeting Overview

James Brett, PCPID Chair

Chairman James Brett welcomed PCPID members to the conference call and thanked them for making time to participate. Mr. Brett apologized to the Committee for the delay in reappointments of the new members. He noted that, because of this delay, he is concerned about the limited preparation time for the 2012 Report to the President. He suggested scheduling a face-to-face meeting in October 2012, in which all members can discuss and agree with only one cutting-edge topic that can be finalized as the 2012 Report to the President by the end of the year.

Approval of Agenda and Minutes (April 06, 2012)

James Brett, PCPID Chair

Liz Weintraub made a motion to approve the minutes for the April 06, 2012 Conference Call. Lillian Sugarman seconded the motion. All other members voted in favor of the minutes, and the motion was carried without discussion.

Discussion Regarding 2012 Report Topic Options

Committee Members

Mark Gross, ex officio representative from the U.S. Department of Justice, asked Chairman Brett to repeat the four priority areas that were discussed during the April 06, 2012 Conference Call. The Chairman responded by listing the four priority topics as follows: Employment, Long-Term Services and Supports, Quality of Life, and Education. Commissioner Lewis recommended that whichever topic the members decide to select for the 2012 Report, should focus on what PCPID can add to the debate that is not already discussed or reported upon by other experts or the Committee itself. Mr. Gross suggested that as the economy starts to recover, the Committee needs to discuss the ways in which the employment opportunities for people with Intellectual Disabilities (ID) can be restored and increased. Lauren Potter agreed and shared with the Committee, that as a self-advocate, she believes that employment has a tremendous effect on the quality of life experienced by individuals with ID. Liz Weintraub expressed that, as a self-advocate, she also believes that employment is really important to individuals with ID. Micki Edelsohn shared that Delaware Governor, Mr. Jack A. Markell, has chosen as his platform the work encompassing the employment of people with disability on a national level. She suggested using the national concepts of employment, not necessarily focused on government hiring, in the 2012 Report to the President. Chairman Brett noted that he has read, on the website of the National Governors Association,

about the initiative undertaken by Governor Markell. He explained that the plan proposed by Governor Markell has a two prong focus on best practices, and creation of blue print for businesses and States to highlight the awareness of the best practices. The Chair also voiced concern that the challenge is how to take from the Governor's plan and put "some meat on the bone," if the Committee were to go-ahead with the suggestion. Ms. Edelson replied that perhaps the Office of Governor Markell can provide PCPID with detailed information regarding the Governor's national employment plans and the engagement of the general public.

Carol Quirk suggested considering the issue of high school preparation programs for students with ID plus transition planning process and job readiness. She noted that there is work of "Think College" and also research by the "National Transition Study" that show the relationship between high school preparation and long-term outcomes for both employment and quality of life. Serena Lowe, representative from the U.S. Department of Labor, agreed with Ms. Quirk and noted that this topic is also time-relevant, given the new study published by the Government Accountability Office (GAO), showing progress in government in terms of strategies for school-to-work programs for students with ID. She pointed out, however, that there is still lack of infrastructure and strategic direction for aligning funding streams, policy objectives, and outcome/performance measures. Ms. Lowe added that the Committee (as a federal presidentially-appointed advisory group) should look at ways in which it can better improve system coordination and collaboration within the federal agencies. She emphasized that the Committee should be cognizant of the important role that education plays in work outcomes for individuals with Intellectual and Developmental Disabilities (IDD). This is in order to determine whether the Committee can converge what is going on in education system with the long-term systems and supports in the report. Carol Wheeler agreed and shared her belief that the topic of education linked to employment is manageable, considering the short amount of time that the Committee has in order to complete the 2012 Report to President. She also noted the importance of the broader employment issue, the minimal progress that has been made in this area, and her hope that the Committee would add its voice to those who are advocating that it become a national priority.

Dr. Deborah Spitalnik pointed out that AIDD leadership and the Committee staff support have moved from the Administration for Children and Families to the Administration for Community Living at HHS, integration of aging and disability is occurring at many levels, and the changes at the state level are important reasons for the Committee to look into Managed Long-Term Supports and Services (LTSS). Mark Gross agreed and suggested that the Committee should address the healthcare issues revolving around the Affordable Care Act (ACA) for people with ID, considering the short amount of time left for the preparation of the report. Carol Wheeler raised concerns that LTSS is a huge issue and may take a longtime for the Committee to research and report on adequately.

Ann Hardiman shared how the state of New York is developing a plan to run its managed care program. She pointed out that part of the funding for developing the plan will be supported by the ACA. Ms. Hardiman shared her belief that it is really disconcerting to her to see how people with IDD currently fit into the managed care model. She added that although the plan under development by the New York State is based on a health model, the person's whole life, including long-term care and acute care, are drawn in and funded under this model. Many pieces that are driven by this medical model are what the service providers historically tried to move away from. For example, when you think about the fundamental piece of this model, "Care Coordination," just "care" is a word that many providers have tried to move away from. Ms. Hardiman suggested that the Committee's report should reflect the degree to which people with IDD are empowered under Managed LTSS, and how progress can be in that area. Lillian Sugerman expressed personal interest in taking on something as bold an different as managed "LTSS for people with ID" and give human voice to it.

Dr. Spitalnik pointed out that one of the roles of the Committee is to make it clear that there is a need to hear the voices of people with ID and their families in the changes occurring in long-term services. She noted that, in order for the Committee to better educate itself, it is necessary to understand many of the terms, definitions and concepts related to long-term services and supports and managed care. Dr. Spitalnik added that what is going on in many states (i.e., New York, North Carolina, Wisconsin, and others) is that Medicaid has provided medical healthcare for people (often referred to as acute care) through managed care organizations, and are now starting to use or consider using managed care organizations for long-term services and supports as well. She explained that State Medicaid agencies are often most concerned about the medical (acute) care part of service delivery through doctors and hospitals, and rely on other implementing agencies (often called developmental disabilities services departments, or aging and disability services departments) for the delivery of long-term services and supports through home and community-based waivers, with many different kinds of community providers. Dr. Spitalnik explained that Managed Care Organizations, who are used to managing people's healthcare through medical services, may not always understand the Medicaid-funded systems of home and community-based long-term services and supports for people with ID/DD, and may have different ideas about what kinds of outcomes may be desired, if they are only looking at things through a medical-model lens. . She raised concerns that if people with ID are part of the larger systems reforms that include the aging community, then the ID/DD community will have a small voice compared to advocacy from AARP (American Association of Retired Persons) and other aging organizations. Dr. Spitalnik suggested that the Committee focuses on raising a public awareness and educating people about MLTSS for people with ID/DD through the 2012 report, providing an important contribution to the discussion revolving around Managed LTSS for people with ID/DD.

Liz Weintraub expressed belief that not many people with ID might be able to fully understand the meaning of Managed LTSS and its implications. Dr. White-Scott agreed similar belief, and emphasized the need for education and public awareness regarding Managed LTSS. She pointed out that a big part of the struggle for the healthcare providers is that the public is not usually conversant with the definition of LTSS and managed care. Yvette Rivera, the representative from the US Department of Transportation, observed that, perhaps, the goal of the Committee through the 2012 Report should be a series of public engagements for the communities of individuals with ID and the greater population to look at ways for capacity building.

Chairman Brett pointed out that it is possible that the sequestration will take effect in January 2013. He expressed belief that, in next five months, the ID community could face a fiscal cliff with respect to issues revolving around human services, Medicare, Medicaid, and Managed Care. Mr. Brett added that the Committee could look at sequestration and its negative impact in the field of IDD and noted that he was aware of no federal Committee looking at the negative consequences for people with IDD of entitlement reforms as being discussed by the Congress or the potential impact of the "Simpson-Bowles" recommendations, in the lives of people with IDD. Dr. Spitalnik added that sequestration and managed long-term services and supports are very connected. She shared her belief that healthcare providers are looking at Managed LTSS not only as different way of providing services but as a way of dealing with budget problems. She continued by saying that a worsened economic situation might force States to choose Managed LTSS faster due to budget shortages. Carol Wheeler suggested that the Committee look into issuing a statement and/or a letter to the President, addressing what would happen in the field of IDD, if sequestration goes into effect. Peter Bell commented that whatever the Committee decides to vote on as a topic should have a sense of permanency and survival, regardless of the 2012 election outcome.

Roll Call Vote on Final Topic Direction

Committee Members

Each member of the Committee was asked to vote on his/her single preferred topic among the following four priority topics for the PCPID 2012 Report to the President: *Employment, Managed Long-Term Services and Supports, Quality of Care, and Education*. The Committee voted, unanimously, for *Managed Long-Term Services and Supports (LTSS)*.

Discussion Regarding Preparation of 2012 Report

Committee Members

Commissioner Lewis pointed out that PCPID staff will invite the participation of a contractor (writer/editor) in Committee discussions regarding the 2012 Report and its recommendations during the PCPID October, 2012 face-to-face meeting.

Nest Steps and Topics Agenda for Next Committee Meeting

Committee Members

Commissioner Lewis asked for suggestions regarding Managed LTSS presenters to be invited to the October meeting, and questions members would like speakers to address during their presentation. Dr. Spitalnik suggested that the first important task is to define all the concepts of Managed LTSS in 101 style. She added that some questions about what is currently happening at the Federal level, and how the Centers for Medicare and Medicaid are funding money and waivers are worthy of exploration. Dr. Spitalnik also expressed that it would be helpful to the Committee to look at the question of how quality of life in the area of LTSS is measured in different settings. Julie Ann Petty agreed and emphasized that it would be helpful to the Committee's self-advocates to learn the different words and ideas regarding Managed LTSS.

Jack Brandt pointed out that he would like to receive information, at the state-level, to understand the changes in managed care in each state. He suggested inviting a representative from the Dual Eligibles/Integrated Care Office to the October meeting. Commissioner Lewis stated that she will work with PCPID staff to propose ideas around how the October meeting agenda should be structured, and encouraged members of the Committee to e-mail their questions and suggestions to staff.

Micki Edelson expressed belief that some of the confusion regarding Managed LTSS revolves around redistribution of funds; thus, it would be helpful to learn about the new ways of delivering the managed care monies. Ann Hardiman agreed and added that the other confusion is that each state can design its own proposal, introducing different approaches to managed LTSS. Dr. Spitalnik commented that perhaps the Committee should take what is learned through the presentations and turn it into a brief educational report. Jack Brandt suggested that the Committee also look at consumer engagement issues.

Commissioner Lewis asked PCPID staff to share the National Council on Disability's "Analysis and Recommendations for the Implementation of Managed Care in Medicaid and Medicare Programs for People with Disabilities" report with the Committee. She noted that it would be helpful to hear from the states that are already implementing LTSS in the managed care environment. Dr. Spitalnik suggested that in order to enhance the presentations by the state representatives, there is a need for submitting standardized questions to all presenters in advance. Ann Hardiman suggested inviting self-advocates,

advocates, and families of people with ID to share their experiences in the states that are already implementing managed LTSS.

Chairman Brett reminded the Committee to respond to the e-mail from PCPID staff regarding the proposed dates for the Full Committee Meeting in October 2012.

Peter Bell made the motion to adjourn. Liz Weintraub seconded the motion. The meeting was adjourned.

Action Items:

PCPID Members

1. E-mail specific questions regarding the Long-Term Services and Supports (LTSS) that would like to receive answers, at the October 2012 face-to-face Committee meeting, to PCPID staff by **Wednesday, August 15, 2012.**
2. Recommended presenters, with particular expertise in LTSS, to speak to the Committee at the October 2012 meeting by **Wednesday, August 15, 2012.**
3. Suggest actions that members may take to become better educated, regarding LTSS, as a Committee by **Wednesday, August 15, 2012.**

PCPID Staff

1. Send to the Committee the links to the National Council on Disability's "Analysis and Recommendations for the Implementation of Managed Care in Medicaid and Medicare Programs for People with Disabilities."
2. Receive all specific questions regarding Long-Term Services and Supports (LTSS) that members would like answered at the October, 2012 face-to-face Committee meeting by **Wednesday, August 15, 2012.**
3. Receive recommended presenters in LTSS, by the members, to speak to the Committee at the October 2012 meeting by **Wednesday, August 15, 2012.**
4. Receive suggested actions, by the members, that the Committee may take to become better educated, regarding LTSS by **Wednesday, August 15, 2012.**
5. Share the National Council on Disability's "Analysis and Recommendations for the Implementation of Managed Care in Medicaid and Medicare Programs for People with Disabilities" report with the members by **Wednesday, August 15, 2012.**
6. Schedule the October 2012 face-to-face Committee meeting by **Wednesday, August 15, 2012.**
7. Prepare the minutes of the August 09, 2012 Committee Meeting by **Monday, September 10, 2012.**
8. Prepare the Draft Agenda of the PCPID October 2012 Meeting by **Monday, September 10, 2012.**



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

Conference Call Agenda

Thursday, August 09, 2012

11:30 a.m. – 2:30 p.m., EST

Toll-Free Dial-in Number: 888-989-0724

Participant Pass Code: 16667

Swearing-in of Eleven PCPID Re-appointees

11:30 a.m. – 1:00 p.m., EST

Welcome and Statement of Occasion

Sharon Lewis

Commissioner, Administration on Intellectual and Developmental Disabilities

Declaration of Appointees' Oath of Office

Sharon Lewis, Officiant

Peter H. Bell

Jack Martin Brandt

Micki Edelson

Ann Hardiman

Alison A. Hillman de Velasquez

Carl M. LaMell

Julie Ann Petty

Lauren Potter

Lillian Sugarman

Carol Wheeler

Sheryl White-Scott

Ethics Training

Catherine A. Hess

Ethics Counsel

Office of General Counsel, U.S. Department of Health and Human Services

Committee Meeting

1:00 p.m. – 2:30 p.m., EST

Toll-Free Dial-in Number: 888-989-0724

Participant Pass Code: 16667

- | | |
|-----------------------|---|
| 1:00 p.m. – 1:05 p.m. | Call to Order and Presentation of PCPID Chair

Sharon Lewis
Commissioner
Administration on Intellectual and Developmental Disabilities |
| 1:05 p.m. – 1:10 p.m. | Welcoming Remarks and Meeting Overview

James T. Brett
PCPID Chair |
| 1:10 p.m. – 1:15 p.m. | Approval of Agenda and Minutes of April 06, 2012 Meeting

PCPID Chair |
| 1:15p.m. – 1:45 p.m. | Discussion Regarding 2012 Report Topic Options

Members

Employment
Education
Quality of Life
Long-term Services and Supports |
| 1:45 p.m. – 1:50 p.m. | Roll Call Vote on Final Topic Direction

Members |
| 1:50 p.m.-2:10 p.m. | Discussion Regarding Experts for October 2012 Meeting and Suggestions for Information Gathering

Members |
| 2:10 p.m. – 2:25 p.m. | Discussion Regarding Preparation of 2012 Report

Members |
| 2:25 p.m. – 2:30 p.m. | Next Steps and Topics Agenda for Next Committee Meeting

PCPID Chair and Members |
| 2:30 p.m. | <i>ADJOURNMENT</i> |