



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

~Minutes~

July 19, 2011 Committee Conference Call

Participants

PCPID Citizen and Ex officio Members and Representatives

James T. Brett, Chair
Annette McKenzie Anderson, Ph.D.
Peter V. Berns
Clay Boatright
Micki Edelsohn
Ann Hardiman
Alison A. Hillman de Velasquez
Carl M. La Mell
Carol Quirk
Susana Ramirez
Deborah M. Spitalnik, Ph.D.

Liz Weintraub
Carol Wheeler
Sheryl White-Scott, M.D
Mark Gross (US Department of Justice)
William D. Falsey (US Department of
the Interior)
Caffin Gordon (US Department of
Transportation)
Michael Caliendo (US Department of
Transportation)

Public Participants

Stefanie Reeves
Mary Ellen Zeppuhar
John Disque

Breck Douglas
Lolli Ross
Audrey Busch

ADD-PCPID Staff

Sharon Lewis, Commissioner
Laverdia Taylor Roach
Madjid "MJ" Karimi
Pamela O'Brien

Sheila Whittaker
Genevieve Swift
Aaron Wiggins, PCPID Intern

~ SUMMARY OF PROCEEDINGS ~

Greetings and Call to Order

Sharon Lewis, ADD Commissioner, PCPID Designated Federal Official

Jim Brett, PCPID Chair

Commissioner Sharon Lewis welcomed Committee members and called the meeting to order. She asked participants to state their name and indicate whether they were members of the Committee or the public. Commissioner Lewis then asked for public comment. No comments were offered.

Chairman Brett requested clarification regarding postponement of the White House event, originally planned for Friday, July 22, 2011, for political appointees. Commissioner Lewis replied that the event was postponed due to weather-related concerns. She explained that members who had a conflict with the July 22nd date would now have an opportunity to RSVP for the event. In response to a question from Dr. Spitalnik, related to lack of email notification about rescheduling of the event, the Commissioner offered assurance that the RSVPs from members had been received, and the lack of notification was due to a mishap.

Regarding transmittal of the PCPID Report to the President, Commissioner Lewis explained that, because neither the Executive Order nor the Charter state a report must be submitted by the end of each calendar year, members should not feel rushed to submit a report by December 31, 2011. As a result of members being sworn in on June 16, 2011, they will have until June 16, 2012 to submit their first report.

Commissioner Lewis then turned the meeting over to Chairman James Brett. Chairman Brett described the purpose of the meeting and encouraged members to express their opinions regarding preparation of the Report to the President. He then turned the meeting over to Subcommittee Co-Chairs, Dr. Deborah Spitalnik and Mr. Peter Berns.

Report Topic and Planning Discussion re Data Gathering Questions

Dr. Deborah Spitalnik, Peter Berns and PCPID Members

Dr. Spitalnik thanked the Commissioner for clarification on the report deadline, and noted that this will give the Committee an opportunity to produce a quality report. She explained that the environment in which the current Committee members work has changed from that experienced by their predecessors. The Committee no longer has the resources to commission extensive works based on conferences with expert speakers or pull in consultants as done in the past. This means that a considerable amount of the work will be done by the Committee through the expertise of its members and self-advocates. Expressing agreement with Dr. Spitalnik, Mr. Brett added that resources are limited and Committee members will be responsible for retrieving data necessary for the preparation of the report. Mr. Berns suggested that members must begin by deciding the content of the report and the Committee's goals.

Dr. Spitalnik acknowledged that the Committee has a richness of experience that can contribute to the report. She then asked members to describe how they want to work together before the next face-to-face meeting on September 26-27, 2011.

Ms. Alison Hillman de Velasquez expressed that the Committee should put forth a report with meaningful recommendations on which the President will be able to act. She added that taking a year to write the report would be unwise, as the President would be unable to enact the recommendations in the midst of the upcoming election cycle. She concluded by offering her assistance in researching and drafting a section of the report.

Ms. Micki Edelsohn advised putting together a first year short-term report, and using the 50th anniversary as the primary focus of the larger report. Dr. Sheryl White-Scott agreed with the suggestion of using the 50th anniversary as a focus of the second report. She emphasized the use of the report as a tool for public awareness. Dr. Annette McKenzie Anderson agreed with a meaningful short-term report and offered her expertise in researching and drafting the first report.

Commissioner Lewis informed Committee members that they are not restricted to a single report format. She explained that the Committee is allowed to submit a variety of correspondence formats (letters, videos, etc.) to advise the President.

Chairman Brett summarized what had been stated previously about a short-term report, and asked if the goal is to prepare the report by the end of the calendar year. Dr. McKenzie Anderson, Ms. Edelsohn and Ms. Hillman de Velasquez responded in the affirmative. Mr. Carl La Mell stated that the December 31st deadline should be a flexible goal, and that quality should be the primary concern.

The Chair and Mr. Berns asked for more elaboration on the intended subject matter of the report as well as the timeframe. Ms. Weintraub agreed with the idea of the short-term report with a December 31, 2011 deadline, and requested that the Committee consider employment as the topic of the report, based on expressed concerns of people with ID that she has encountered in her work. She explained how employment is crucial to achieving full community participation.

Mr. Mark Gross noted that public awareness has been on the Committee's agenda for many years and remains a difficult topic to address. He agreed with the suggestion of considering employment, as it is the key to the independence of people with ID. In response to concerns expressed by Mark Gross, Dr. Spitalnik suggested using public awareness as a component of the final strategy to accomplish the Committee's goals. She explained how the Committee had agreed, during the full Committee meeting of June 16-17, 2011, that full community participation should be considered the overarching goal of the Committee. Dr. Spitalnik added that employment could be used as a more salient aspect, with support coming from resources including: self-advocates; work of the prior Committees; recommendations from the Alliance for Full Participation in November; and, ADD's funding of Projects of National Significance. Dr. Spitalnik concluded that other areas, outside of employment, could be considered in the larger second report. Ms. Edelsohn agreed with these suggestions and explained that the Committee should call on companies and corporations such as Marriott, MBNA/Bank of America, and Project SEARCH at Cincinnati Children's Hospital, all of which have been recognized and won awards for employing people with ID. Dr. Spitalnik replied that this could be an interesting component of a multi-dimensional approach to employment. She then expressed concern about what is happening with the Affordable Care Act (ACA) and the inclusion of people with ID, especially as it relates to long-term care.

Mr. Berns requested that, before delving into the specific topics, the Committee clarify exactly what success will look like. He asked that members speak on why the 50th anniversary is significant to them. Ms. Susana Ramirez stated that the 50th anniversary could be a great tool for advocating for increased public awareness. She also reemphasized having flexibility with the timing of the report, as suggested by Mr. La Mell. Mr. Gross agreed with conducting a comparison of the lives of people over the past 50 years. He explained how his experience has shown him that the lives of children have been hugely enhanced as a result of the American with Disabilities Act (ADA). However, this advancement is significantly less in adults once they leave the world of education, and the anniversary gives a great opportunity to call attention to this fact. Dr. White-Scott agreed with this observation and considered the 50th anniversary to be a wonderful milestone. She stated that the anniversary could be considered a vehicle for not only public awareness and reflection but also to look at the issues of transition, employment, and the ACA. The report should highlight some key issues and show how the nation needs to move forward in regards to the lives of people with ID. She also explained how this could be accomplished through different types of media, such as a letter or a video. Dr. McKenzie Anderson considered the anniversary as a great opportunity to show the past, present, and future of ID and increase public awareness in pursuit of full community participation. She also highlighted some areas where people with ID are now included, such as post-secondary education and fine arts programs.

Mr. Berns stated that, from his perspective, the 50th Anniversary is significant for two reasons: 1) the anniversary presents an opportunity to reflect on what has been accomplished, and what remains to be done; and 2) it provides the chance to produce something that is of great significance, similar to what was done by the first Presidential Panel.

Ms. Hillman de Velasquez proposed that the Committee construct a well-written, focused report with recommendations on employment first; then, focus on the 50th anniversary in the second report. She also suggested connecting the issue of transition to employment. She then asked Commissioner Lewis or Ms. Laverdia Roach about whether the Committee can only submit one report each year. Commissioner Lewis emphasized that limited resources may serve as a restraint to the production of numerous correspondences but the Committee does have the freedom to submit several reports, letters, etc. Mr. Clay Boatright agreed with the idea of having two reports and stated that the Committee could compose a report on employment, which would be of minimal expense by consolidating reports already available. This approach would also have a greater potential to impact the budget process that begins in March. Simultaneously, the Committee could begin work on a long-term report that takes into consideration the 50th anniversary but also seeks to make a substantial impact. In order to have this impact, the Committee would need to determine a report theme that is innovative. In response, Dr. Spitalnik highlighted the accomplishment of the Blue Ribbon Panel's report, which suggested the need for federal and state governments to make public policy on behalf of people with ID. She suggested that the Committee could illustrate how to make public policy work for this population in a wide range of areas. Dr. Spitalnik explained how, in the history of the Committee, there were multiple reports produced in one year. She suggested that the Committee should place the deadline of a report on employment at a point in time where it could have an impact on the federal budget, and asked Commissioner Lewis what about the best time to submit this kind of report. Ms. Lewis replied that the President announces his plan for the federal budget for the following fiscal year in February. The deadline for influencing the budget for FY13 has passed. The next proposal cycle will begin in March 2012, which will create the budget for FY14, and the best time to have a report available is during the spring.

Ms. Carol Wheeler asked about the status of staff efforts to gather recommendations from past reports and examine their implementation by the governmental departments and agencies. Ms. Roach replied that Committee members received a flash drive containing two documents: one citing all recommendations included in PCMR/PCPID Reports to the President and another citing categories of recommendations based on what is considered the responsibility of each of the thirteen PCPID ex officio member departments or national organizations. She expressed belief that determining the degree of implementation of recommendations contained in early reports may prove a challenging task.

Chairman Brett asked if the anniversary report would be due in January 2012. Dr. Spitalnik replied that the Committee seems to want a more immediate report, which would focus on employment, and a separate report for recognizing the 50th anniversary. Ms. Hillman, Ms. Edelson, Ms. Wheeler, and Ms. Weintraub supported Dr. Spitalnik's sentiment. Mr. Boatright advised that the Committee should try and have its first report submitted by the end of February, in order to impact the federal budget planning process. Ms. Wheeler agreed with this idea and advised that issues such as transportation and transition supports be included in the realm of employment.

Ms. Weintraub expressed belief that self-advocates need to be involved in the preparation of the report and wanted to know how the Committee would gather the self-advocates' input if the new self-advocates have not been appointed to the Committee. Dr. Spitalnik stated that the Committee will find ways to include the opinions of self-advocates in the report. Ms. Ramirez supported the idea of having self-advocates be at the forefront and expressed her hope that employment be viewed as a step towards full community inclusion.

Considering the recent PCPID report submitted in 2009, Mr. Berns asked if the Committee would have something new to add to the area of employment. Dr. Spitalnik expressed belief that the Committee would have something new to add because there are current events that should be brought to bear, such as the Department of Labor's funding of the National Technical Assistance Center for Employment in New Jersey. These events can be related to Ms. Edelson's earlier suggestion to look into companies that hire people with ID. In light of the economic downturn, the Committee must be sure that people with intellectual disabilities are included in plans for the recovery.

Commissioner Lewis asked the following questions: a) What does the Committee have that is new or newly relevant to the area of employment that could be introduced in the report? b) How do those things tie into potential recommendations? In response, Dr. Spitalnik suggested that the Committee use the August meeting to come to a consensus on the report topic and how the anniversary should be used and develop some form of a structure and planning. Then, in September, the Committee would begin work on both the short-term and long-term reports. Dr. McKenzie Anderson, Ms. Hillman, Ms. Ramirez, Dr. White-Scott and Ms. Edelson agreed with Dr. Spitalnik's suggestion.

Mr. La Mell interjected that he believed the focus of the report should not be solely on employment, but on healthcare and health insurance. Dr. Spitalnik supported his belief and asked for Dr. White-Scott's perspective, considering her specialization in the medical field. Dr. White-Scott suggested that there is a way to consider both employment and healthcare if the

subject of employment is viewed broadly enough. Ms. Wheeler added that the Committee could also write a letter to the President on that subject in conjunction with the report.

Dr. Spitalnik then asked Commissioner Lewis if she had any suggestions, considering her role as the head of the Administration of Developmental Disabilities. The Commissioner explained that, from the Department of Health and Human Services' perspective, there is certainly a focus on implementation of the ACA and the provisions that are beneficial to people with ID and their families and on how changes at the state level will affect investments into Medicaid. She emphasized that healthcare and health insurance was a timely topic. Commissioner Lewis also explained how the Centers for Medicaid and Medicare Services (CMS) are looking at rule changes about how home and community is defined. She shared that Section 2402A of the ACA "requires the Secretary to promulgate regulations to ensure that states are implementing systems of home and community based services that ensure that beneficiary choice and the opportunity to pursue a self-directed, independent life." This is a section of the ACA which people with ID would likely be concerned about.

Dr. Spitalnik highlighted initiatives going on within the Centers for Disease Control and Prevention's (CDC) National Centers for Birth Defects and Developmental Disabilities. These initiatives relate to the Committee's commitment to prevention and the expansion of the knowledge of intervention and early onset disabilities. Mr. La Mell reemphasized that this was the time to develop the right policies about healthcare as these decisions would have long-lasting effects.

Dr. Spitalnik outlined options the Committee has regarding the short-term report: focus on employment, the ACA, or both; or, focus on one topic, while a small working group researches other issues and reports findings to the Committee as a whole. Such findings could be presented to the President in various forms (e.g., an action alert or a letter). Dr. Spitalnik asked whether the members should decide on the short-term/long-term report ideas while leaving the topic material open for further debate. Dr. White-Scott advised that this ramification of the process should also include the deadlines for both reports. Commissioner Lewis, after reaffirming Dr. Spitalnik's statement of the inability to vote during this conference call, advised that members should focus on ways to bring something concrete for the full Committee and that this could be done through email.

Commissioner Lewis reminded the Committee that half of the PCPID members were appointed for a year [May 2012] and the other half were appointed for two years [May 2013] and that this should be kept in mind when considering the timeline as there could be a change in membership next year. She explained that each member should know when his/her appointment expires. This information will be made available to Committee by the staff.

In response to Dr. Spitalnik's request for an update on the status of appointment of more self-advocates to the Committee, Commissioner Lewis explained that she was unable to give an exact date, but that two lists have been submitted with potential self-advocate appointees. She also stated that reappointments of current members were at the discretion of the White House. Ms. Weintraub asked if the Committee was allowed to reach out to self-advocates through other means while it awaited the appointment of self-advocate Committee members. The Commissioner responded that it was important for the Committee to use other resources. She explained that it would be possible to invite self-advocate speakers to the upcoming September meeting if they were able to give some insight into the current issues.

Mr. Berns suggested that he and Dr. Spitalnik, as co-chairs of the “Subcommittee on Report Topics and Themes,” use notes from the meeting to draft a written proposal that addresses the two reports, the timeline, and the role of Committee members in preparing the report. In the meantime, two small groups could each develop one point-of-view presentation (one on employment and one on the ACA/Medicaid) that defends why that particular theme should be the topic of the first report, and what the report would look like. These pitches would be presented at the August 16, 2011 full Committee conference call. Dr. Spitalnik advised the two groups to keep in mind that there are other forms of media available. Ms. Hillman de Velasquez and Chairman Brett supported this idea, and Dr. Spitalnik asked for volunteers for the two groups. Volunteers for the employment working group were: Elizabeth Weintraub, Carol Quirk, Micki Edelson, Carol Wheeler, and Dr. Annette McKenzie Anderson. The group for Medicaid/ACA is composed of Alison Hillman de Velasquez, Dr. Sheryl White-Scott, Dr. Deborah Spitalnik, Peter Berns, and Carl La Mell.

Dr. Spitalnik asked whether the members would prefer sharing a paper defending their suggested topic for the report, or making an oral presentation. Mr. Berns replied that someone from each group should prepare to present the pitch with an accompanying paper that is disseminated to Committee members. Dr. Spitalnik suggested that members of the groups begin exchanging emails in preparation for the August meeting. Ms. Hillman de Velasquez asked that all those who volunteered for ACA/Medicaid send her an email. She then volunteered to chair the ACA/Medicaid focus group. Ms. Carol Quirk agreed to chair the focus group on employment. Ms. Ramirez suggested that the Committee should also look into doing a short-brief or another type of correspondence for the topic not chosen. She also asked whether there was an exact time frame for the short-term report. Dr. Spitalnik advised that they make this decision after determining the topic during the August meeting. Commissioner Lewis made a request of the two work groups that they also advise on resources and individuals for the Committee to consider, and as they compose their presentation, keep staff informed, in case there are individuals who should be invited to the September meeting.

Dr. Spitalnik also reminded members of the upcoming Alliance for Full Participation Conference in Washington, DC that will be held from November 17-19, 2011.

Chairman Brett commended staff, Committee members, and Subcommittee co-chairs before bringing the meeting to close.

Ms. Roach announced that minutes of the conference call would be made available to the Committee early next week (July 25, 2011).

Action Items:

Committee Members:

- 1) Inform staff of individuals who should be invited to the September face-to-face meeting as speakers/presenters.

Co-Chairs of Subcommittee:

- 1) Use notes and minutes from the meeting to draft a written proposal that addresses the two reports, the timeline, and the role of Committee members in preparation of the report.

Volunteer Working Groups:

- 1) Develop a POV presentation that:
 - Defends why the recommended theme should be the topic of the first report
 - Describes what the report would look like if based on the recommended theme
 - Identifies resource materials and guest speakers with expertise regarding the recommended report theme, for Committee consideration
 - Identifies optional formats (letter, position paper, action alert, etc.) that may be used to advise the President on the topic
- 2) Inform staff of individuals who should be invited to the September face-to-face meeting as speakers on issues facing the disability community related to report theme supported in POV presentation.

NOTE: Committee members interested in volunteering for the ACA/Medicaid working group should send an email to Alison Hillman de Velasquez.

PCPID Staff:

- 1) Convert the meeting recording into minutes.
- 2) Share, with the Committee members, a list of when the members' appointments expire.
- 3) Send email to ex officio members asking that they begin reviewing recommendations from past reports and determining their status of implementation.

Suggested Agenda for August Meeting by Dr. Deborah Spitalnik:

Discussion of the two presentations/papers

Selection of Report theme and format

Decision of how to handle theme not chosen

Discussion of how the Committee will organize to perform tasks related to preparation of the report(s).