



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

~Minutes~

Committee Conference Call

February 01, 2012

1:00 p.m. – 2:30 p.m., EST

Participants

Citizen and Ex officio Members and Representatives

James T. Brett, Chair

Annette McKenzie Anderson, Ph.D.

Peter V. Berns

Clay Boatright

Micki Edelson

Ann Hardiman

Alison A. Hillman de Velasquez

Carl M. La Mell

Julie Petty

Lauren Potter

Carol Quirk

Susana Ramirez

Deborah M. Spitalnik, Ph.D.

Lillian Sugarman

Liz Weintraub

Carol Wheeler

Sheryl White-Scott, M.D.

Michael Caliendo (US Department of
Transportation)

Margaret Schaefer (US Department of
Homeland Security)

Jewel Bazilio-Bellegarde (Corporation for
National and Community Services)

Leola Brooks (US Social Security
Administration)

Mary Kay Mauren (Equal Employment
Opportunity Commission)

Gary Blumenthal (National Council on
Disability)

Special Guest(s) [Committee appointees, not sworn-in]

Peter Bell

Jack Martin Brandt

Public Participant(s)

Robin Sinkhorn

ADD-PCPID Staff

Sharon Lewis, Commissioner

Laverdia Taylor Roach, Senior Advisor

Madjid "MJ" Karimi, Program Analyst

Sheila Whittaker, Program Assistant

Summary of Proceedings

Greetings, Call to Order and Presentation of PCPID Chair

SHARON LEWIS, ADD COMMISSIONER, PCPID DESIGNATED FEDERAL OFFICIAL

Commissioner Lewis welcomed participants and introduced Lauren Potter and Julie Ann Petty

(Committee members who have been officially sworn-in to PCPID since the last Committee Conference Call in November 2011). The Commissioner also welcomed Peter Bell and Jack Martin Brandt, PCPID appointees who have not yet been officially sworn-in to the Committee.

Welcoming Remarks and Meeting Overview

JAMES BRETT, PCPID CHAIR

Chairman Brett welcomed participants.

Introduction of PCPID New Members

JAMES BRETT, PCPID CHAIR

Chairman Brett acknowledged the two new Committee appointees and invited them to introduce themselves. Each appointee provided a brief introduction, including background information and their interest in intellectual disabilities (ID).

Approval of Agenda and Minutes (November 14, 2011)

JAMES BRETT, PCPID CHAIR

Chairman Brett proposed a vote on the agenda for the current meeting and the minutes for the November 14, 2011 conference call. Allison Hillman made a motion to adopt the agenda and the minutes. Liz Weintraub seconded the motion. The motion was unanimously accepted.

Status of the 2011 PCPID Report to the President and Related Questions

SHARON LEWIS, ADD COMMISSIONER, PCPID DESIGNATED FEDERAL OFFICIAL

Commissioner Lewis congratulated Committee members and staff for their work on the 2011 Report to the President, especially considering the quick timetable. The Report went through the Department of Health and Human Services (HHS) clearance process with only minor changes and edits, but nothing substantive. The Commissioner learned this morning, from the Office of HHS Secretary, that the Report and transmittal letter were both awaiting Secretary Sebelius' signature. Once signed, the Report should be sent to the White House within the next 48 hours. At that time, Committee members will be informed and the Report will be posted to the PCPID Website. The current administration intends to allow automatic posting of PCPID Reports on the Committee's website. Commissioner Lewis noted that all individuals from HHS who reviewed the Report were impressed with its clarity, depth, and applicability to current issues, given the time constraints.

Chairman Brett also thanked Committee members and staff for their work on the Report to the President.

Liz Weintraub asked whether the Report will be available in an alternative format for people who are visually impaired. The Report will be posted on the website in an accessible 508-compliance Portable Document Format (PDF). If individuals need the Report in a different accessible format, it will be available upon request.

Discussion Regarding PCPID 2012 Agenda

ALL

Commissioner Lewis briefly updated the Committee regarding the HHS recent activities and efforts. Continued implementation of the Affordable Care Act (ACA) is a priority to the current administration. There have been significant announcements in recent months regarding opportunities for states to pursue innovation as it relates to Medicaid and Medicare, particularly as it relates to those who are dually-eligible under both programs. This included a significant number of people with ID. The new Innovation Center is going to be a tremendous resource to move the conversation forward in terms of healthcare reform within the next five years. Within the context of that conversation, an important component has been discussion and the move towards Accountable Care Organizations, also known as Coordinated Care Organizations, and Managed Care. The Administration on Developmental Disabilities (ADD) staff and other HHS employees have been examining what this means for long-term services and supports paid for by Medicaid, including many programs of interest to the Committee. ADD staff has been looking at how these managed care organizations and the implementation of these changes will impact services. It should be noted that this was not discussed as a potential topic for the 2012 Report, but it intersects with topics that were suggested. For example, it relates to the implementation of the ACA and the idea of community living. This change is significant and complex and will impact every aspect of Medicaid and Medicare services in the future.

Gary Blumenthal asked whether data exists on the impact of the ACA on dual-eligible individuals. Data is needed to determine whether the impact will be positive, negative, or neutral. In Massachusetts, for example, there is an effort to get a “carve-out” done regarding this question. Gary expressed his hope that ADD will be the repository of data on this issue.

Sharon Lewis agreed that the data is limited. Part of the intent, when looking at Innovation Center resources and grants, is to think about these changes and how they may look in the future. For states that “carve this out” in the short term, it will be hard for Intellectual Disabilities and Developmental Disabilities (ID/DD) systems to disconnect that far from the rest of the Medicaid system. The question is whether it can be done in a thoughtful, planned way. Some of the advocacy groups have begun to circulate documents with principles. If PCPID members are interested, that information can be located and provided to them. This may help members to think about the things that need to be considered as systems move in this direction. ADD is trying to determine where to find the best data and information to help accomplish this. Some states have gone to Managed Care in terms of long-term services and supports. The questions are: a) to what degree this is well integrated into the account care side, and b) how those pieces all come together. The end-result remains to be seen. Commissioner Lewis turned the time over to Chairman Brett for discussion of the 2012 agenda. The Chair recommended that, for the 2012 Report, the Committee choose one issue and go into depth about that single issue.

Peter Berns reminded Committee members about the 50th anniversary of President Kennedy’s establishment of the Blue Ribbon Panel that led to the creation of PCPID. He believes that this presents an opportunity to examine the status of people with ID after 50 years. Additionally, one role of this Committee may be to step back from the status quo and examine new, big ideas that could be put on the table. PCPID might also consider using currently available data to determine the kind of system that would be ideal if redesigned with the knowledge gained over the last 50 years. The Committee, for instance, could look at the current service delivery system, which is financed largely through Medicaid, and income supports, financed mainly through Supplemental Security Income (SSI).

Deborah Spitalnik pointed out that the shifts in Medicaid and Medicare policy, discussed by Commissioner Lewis, are basic to nearly every issue that the Committee might consider because Medicaid pays for many support programs. The Committee might provide a great service by looking at these shifts, focusing on the meaning behind them, and educating the ID community about them. If the Committee picks a subtopic, the shifts may render the topic inapplicable because of changes in the larger landscape.

Liz Weintraub stated that she liked Dr. Spitalnik's idea, but she reminded Committee members that this is an election year. She believes that if there be a change in Administration, some of the new policies and initiatives may be wiped away because of economic issues.

Julie Petty agreed with Peter Berns and Deborah Spitalnik. She, however, suggested that the Committee consider a Report to the President about independence and community inclusion. Many people with ID still live in segregated settings. The data shows that the quality of life is not as good as it could be. She expressed her desire to look at independence with the right services and supports.

Carol Quirk pointed out that the Committee's charge is to make recommendations regarding full participation for people with ID. She suggested that the ideas of Peter Berns and Julie Petty should be combined into a report that looks at the kind of data that is reported by David Braddock in the publication, *State of the States in Developmental Disabilities*. The Medicaid and Medicare policies do have an important impact, but the PCPID may want to take a broader view, making sure to include these policies and practices in a discussion of necessary changes to improve in this area.

Carol Wheeler suggested pinpointing a broader topic, and Clay Boatright agreed. Clay expressed that the Committee could conceptualize a new idea of the support system, leveraging both government and non-government supports. He added that the Committee did a good job of conceptualizing the current situation and specific concerns in the 2011 Report. The 2012 Report could follow up with a powerful, forward-looking redesign of the current system, which brings-in elements that do not yet exist. This could lead to a system that is significantly more sustainable than the current one, an important feature in today's financial climate.

Carol Wheeler agreed with Clay, but pointed out that she would like to see greater emphasis on employment. Sustainability would be much more likely if individuals with ID had real jobs. As the Committee works on these issues, it needs to figure out how to get more national attention in the broader business community and inform people about the things being accomplished by and for individuals with ID (at that time labeled mental retardation). Chairman Brett asked Carol Wheeler whether there is anything in the PCPID 2009 Report to the President that can be used or be taken to a higher level. Carol responded that while she could not specify anything at that moment, she felt the 2009 Report contained good information and recommendations with respect to employment and that it was worth taking a another close look.

Deborah Spitalnik suggested that PCPID consider merging the ideas expressed by Committee members. The purpose of the original Blue Ribbon Panel was to get federal policy to focus on the needs of people with ID. At this point, a great deal of federal policy has been developed to undergird systems for people with ID. Part of PCPID's historical responsibility is to actively address the needs and desires of people with ID by influencing policy during the current system transformation. Using the existent body of policy, the Committee can take the perspective that Peter Berns suggested and figure out: a) what transformational ideas could improve the system, and b) how to set those ideas forth in the 2012 Report? If the Committee focuses on one specific subject, it runs the risk that changes in state and federal

governments will render the PCPID Report unhelpful to people with ID. For that reason, the Committee should look at policy broadly and comprehensively.

Chairman Brett agreed, and explained that his initial suggestion of a single report topic was due to the limited resources and staff available for completing a report. Members will need to research and write the report themselves. Gary Blumenthal reminded members that, in the past, the Committee has partnered with other entities to help provide resources. In addition, PCPID was realigned under the ADD for the purpose of sharing staff resources. Mr. Blumenthal asked the Commissioner to comment on whether resources will be available from ADD.

Sharon Lewis responded that the limit on resources has affected the entire government. ADD's discretionary resources were reduced by over 40% for the FY12 budget. She noted that the PCPID Charter provides a fairly nominal budget. The Committee, however, should still consider what it would like to accomplish. At the last face-to-face meeting, the facilitator was provided through ADD resources. The important question in the current discussion is the topic of the 2012 Report and the overall approach that the Committee wants to take.

Deborah Spitalnik pointed out that, in addition to creating a report, the Committee has a role in advising the Secretary of HHS and the President about issues affecting people with ID. Given PCPID's location within ADD and HHS and the level of activity within HHS on the structure of programs for people with ID, there is an imperative for PCPID to be a voice in that process.

Carol Quirk suggested that, for the 50th anniversary, a larger picture is needed. Shifts in Medicaid and Medicare policy are important, but policy affects people with ID throughout various parts of their lives. People with ID are still not included as a major part of society. Many are not given access to services, which sets the stage for a limited life experience.

Micki Edelson agreed with Carol Quirk and suggested that Committee members take a small poll to determine the broadness of the next report. There is a lot of history in this area. The Arc survey last year from Peter Berns can be used to illustrate Carol Quirk's point that, although the field has come quite a long ways, there is still a long way to go.

Carol Quirk pointed out that, if the Report focuses on the progress and changes that are still necessary, Medicaid and Medicare policy will be addressed in the recommendations section of the Report to the President. There might also be an opportunity to discuss personnel preparation and the fact that society is not setup in a way to facilitate full community participation.

Dr. Spitalnik expressed concern that, if the Committee addresses the issue on an abstract level and policy is being set that leans towards a medical model, then the course of the money will be set in that direction and the Committee's recommendations will not have any connection. She noted that unless the Committee understands the larger conversation, the recommendations will be set without consideration for the needs of people with ID. Dr. Spitalnik also suggested that part of the next meeting should be spent on educating Committee members to draw on what is happening in HHS. Medicaid and Medicare policy may be the only vehicle available for transformative ideas.

Susana Ramirez agreed that the Committee needs to be tied to policy and must be present to provide guidance while policy is developing and changing.

Peter Berns questioned whether PCPID can have a timely impact on issues that are already under deliberation. He cited the PCPID 2011 Report to the President as an example: It did not affect the policy

making process because the deliberation was completed before the Report was finalized. Influencing current policy should be left to the other advocacy organizations. A more important role for the Committee is to look at the bigger picture and generate new ideas. Peter Berns suggested putting on an invitational conference, which would include the best thinkers in areas related to ID and asking them to brainstorm specific ID related questions.

Gary Blumenthal stated that the Committee in 1990s, had done what Peter was suggesting. The resources for a conference like this are however extremely limited. He suggested that the Commissioner discuss the ideas from this call with her staff and bring back a work plan with recommendations based on available resources.

Sharon Lewis expressed a desire to have consensus of the Committee membership regarding the Report topic(s) and data-gathering tools/methods.

Liz Weintraub reminded the Committee that these topics are of interest to self-advocates, and it is important to include them in this dialogue.

Ann Hardiman thought that the Committee might agree on a report that recognizes the 50th anniversary and discusses how much farther community inclusion must go. She suggested that Committee members could use their connections, rather than a conference, to gather innovative ideas from individuals in the ID community. The Committee can pose specific questions to be addressed and use a website or other alternative to gather this information.

Cheryl White-Scott agreed with the big-picture idea tied back into the 50th anniversary. She expressed belief that this is a great opportunity to push the envelope to improve the quality of life for people with ID.

Sharon Lewis suggested going back to the 1967 Report, which is mostly quite broad and using it as a framework and starting point. The report would cover where the country was, where it is now, and where the Committee would like to go. This would provide an opportunity to acknowledge policy issues that members want to address. Such a report would be a substantial undertaking. The Report could cover all the topics addressed in conference call (February 1, 2012). It would not, however, provide the opportunity to be extremely specific about policy.

Gary Blumenthal asked whether a Center of Excellence might want to write the Report. Commissioner Lewis acknowledged that someone at one of these Centers might want to donate their services, but she could not commit anyone to do the work.

Sharon Lewis stated that once a topic for the Report is settled, the details of resources and execution will be worked out. Commissioner Lewis pulled the discussion back to the broadness and the framework of the report. She clarified that the 1967 Report to the President is a good framework because it reviews the first five years of the Blue Ribbon Panel and the Committee.

Alison Hillman suggested a vote on Commissioner's idea, including a broad framework, a discussion of the past, present, and future, and input from experts. Members voted in the affirmative.

Commissioner Lewis made an effort to clarify what the vote entailed. She suggested that the Committee wanted to gather expertise to address topics set by the Committee. This can provide the Committee with information.

Lillian Sugarman suggested inviting the experts before the next face-to-face meeting. Additionally, self-advocates should be included as experts.

Dr. Spitalnik volunteered to be in charge of looking at historical information and drafting the agenda. She will examine each of the recommendations from the 1967 Report to the President, highlight each recommendation, and analyze the outcomes of each recommendation in today's context. Liz Weintraub requested that one of the Committee's self-advocates be involved in that process. Deborah Spitalnik noted that she will not be able to complete this task until late April or early May. Carol Wheeler and Sharon Lewis expressed concerns that the Committee needs to move more quickly than that. Deborah Spitalnik suggested that the current information was already identified in the 2011 Report and the historical information does not necessarily need to be done for the current portion to be completed.

Commissioner Lewis mentioned the possibility that the next face-to-face meeting might take place in April or May. She suggested that PCPID staff and come up with a framework for accomplishing the Committee's plan for the report. That plan is to ground the Report in the historical 1967 Report to the President, discuss progress, and produce future-looking recommendations with the assistance of experts. Sharon Lewis pointed out that a call will be scheduled in approximately one month that will allow Committee members to adopt the framework produced by the PCPID staff. The experts will be invited to a face-to-face meeting, rather than a conference call.

Carol Wheeler suggested that the 50th anniversary is a tool for getting people to pay attention to the issues related to ID. She noted that Committee members should be thinking ahead of time about how to bring increased attention and who needs to participate in this effort.

Commissioner Lewis and Chairman Brett have been brainstorming ways to celebrate the anniversary. The celebration will most likely take place during the summer because of the election cycle. No decisions have been made, but the issue is being discussed. It is unlikely that the Report will be ready in time for the celebration, if that celebration happens in the summer. The anniversary will need to be celebrated, separately, on each of these occasions.

Carol Wheeler reminded Committee members not to forget the national press. She invited guidance from Sharon Lewis about an appropriate role for raising this issue with individuals they might know in the press. There will most likely be some national press about this event.

Sharon responded that it depends on the direction that the Committee decides to take with the anniversary event and the Report. If Committee members decide to flag the report for the media and work those channels, they would be welcome to do so. With regard to the anniversary event, media involvement would depend on the type of event and the individuals involved.

Sharon Lewis, once again, asked for consensus on the plan for the report. The Committee staff will build a framework based on the 1967 Report with an acknowledgement for where we are today. This will be very broad. From that point, Committee members will be able to propose experts to engage for a face-to-face meeting in late spring. Another conference call will be schedule to discuss the framework for the Report and the plans for the face-to-face meeting.

Carl LaMell asked for dates for the face-to-face meeting. Chairman Brett proposed several dates for the conference call and face-to-face meeting: April 9th and 10th or April 16th and 17th. Sharon Lewis reminded the Chair that, during the conference call in late March, Committee members will choose the experts. If the face-to-face meeting takes place five weeks after the conference call, in April, some experts may not be able to attend on such short notice. The Commissioner suggested that she look at the calendar and

possible conflicts and settle on a date via e-mail. The face-to-face meeting will most likely take place in late April or early May.

Clay Boatright suggested that the Committee Meeting might be scheduled to coincide with the Disability Policy Seminar. Deborah Spitalnik expressed her concern that the combination of events might appear to be a conflict of interest. Chairman Brett confirmed that members would wait to hear from PCPID staff for scheduling.

Carl LaMell made a motion to adjourn the meeting. The motion was seconded by a number of Committee members. The motion was unanimously accepted. The meeting was adjourned.

Action Items:

Committee Members

Think about how to bring increased attention to the 50th anniversary of PCPID and who needs to participate in this effort.

PCPID Staff

- Convert the meeting recording into minutes.
- Come up with a framework for accomplishing the Committee's plan for the report.
- Look at historical information. Examine each of the recommendations from the Committee's 1967 Report to the President, highlight each of the ten recommendations, and analyze the outcomes of each recommendation in today's context.
- Schedule a conference call for March, and a face-to-face meeting for April or May 2012.