



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

Committee Conference Call

April 06, 2012

~Minutes~

Participants

PCPID Citizen and Ex officio Members and Representatives

James T. Brett, Chair	Deborah M. Spitalnik, Ph.D.
Annette McKenzie Anderson, Ph.D.	Lillian Sugarman
Peter Bell	Liz Weintraub
Peter V. Berns	Carol Wheeler
Clay Boatright	Sheryl White-Scott, M.D.
Jack Martin Brandt	William D. Falsey (US Department of the Interior)
Micki Edelson	Janine Villez (US Department of Housing and Urban Development)
Ann Hardiman	Charlie Lakin (US Department of Education)
Alison A. Hillman de Velasquez	Dawn Carlson (US Department of Education)
Carl M. La Mell	Jerry Elliot (US Department of Education)
Julie Petty	Gary Blumenthal (National Council on Disability)
Lauren Potter	
Carol Quirk	
Susana Ramirez	

ADD-PCPID Staff

Sharon Lewis, ADD Commissioner	Sheila Whittaker
Laverdia Taylor Roach	Genevieve Swift
Madjid "MJ" Karimi	

Summary of Proceedings

The Meeting began with a roll call. Jerry Elliot will be listening in for Jennifer Sheehy and Janine Villez will be listening in for Michelle Aronowitz.

Greetings, Call to Order, and Presentation of Chairman

SHARON LEWIS, ADD COMMISSIONER, PCPID DESIGNATED FEDERAL OFFICIAL

Sharon Lewis, PCPID DFO, called the meeting to order and turned the time 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 attend. He also reminded members of the May 17th and 18th face-to-face meeting.

Introduction of New Members

JAMES BRETT, PCPID CHAIR

Chairman Brett welcomed Peter Bell and Jack Brandt, who have been officially sworn in since the last meeting.

Approval of Agenda and Minutes (February 01, 2012)

JAMES BRETT, PCPID CHAIR

Allison Hilman de Velasquez made a motion to approve the minutes for the February 1, 2012 conference call. Micki Edelson seconded the motion. Lauren Potter objected to the adoption of the minutes. The ADD Commissioner inquired whether Ms. Potter had a comment regarding the minutes and whether changes could be made that would cause her to support the adoption of the minutes. Ms. Potter insisted that she understood the purpose of the vote and modifications to the minutes would not change her objection. She went on record as opposing the adoption of the minutes. All other members voted in favor of the minutes.

Discussion of the 2012 Report to the President

COMMITTEE MEMBERS

Jim Brett asked that the 50th anniversary be added to the agenda for the May meeting. It should be used to focus attention on the issues related to intellectual disability (ID). PCPID should spend time on the first day of the Committee meeting figuring out how to best use the moment. PCPID could focus on public-private partnership or the best method to get the message out. Chairman Brett mentioned a former national correspondent who might be interested in helping PCPID to use this opportunity to get this message out most successfully. He thanked the Committee members who had already started to focus on this issue.

Clay Boatright liked this idea and expressed his desire to take advantage of this one-time opportunity by highlight an area that is important and contributes something new to the body of knowledge.

Deborah Spitalnik emphasized the importance of understanding the history of people with ID while looking forwards. Generations have grown up with the expectation of education and employment. PCPID needs to examine how this progress was made possible. Those services, which people have come to expect, are fragile. PCPID needs to work to protect them.

Annette McKenzie Anderson asked to be a part of any group working on planning for the 50th Anniversary prior to the May meeting.

Jim proposed that the working group that existed in the past be expanded to include more people. Carol Wheeler, Micki Edelson, and Deborah Spitalnik will lead the planning for the 50th Anniversary celebration. Julie Petty suggested that a person with a developmental disability should be on the work group and volunteered herself.

Sharon asked whether this would be an official work group. Chairman Brett wanted to avoid having it classified as an official work group. In order to do so, the members of the group will need to form an ad hoc group that can generate ideas. If the group wants to make official decisions, it will need to be considered an official work group and announced in the Federal Register. Members interested in volunteering will send an email to MJ after the call. MJ will compile and disseminate a list of volunteers to discuss option related to the 50th Anniversary celebration.

Peter Berns would like the Committee to focus on how PCPID can have more impact, influence, and visibility and be more of an agent for change, as in the past. He suggested that PCPID revisit the charter at the next Committee meeting and consider suggesting changes to the charge of PCPID for the next 50 years. The charge could be expanded to include more than just a Report to the President.

Peter Bell expressed his support for Peter Berns' idea.

Carol Quirk asked whether this topic might be put off for a future meeting because of the limited time available during the May 2012 meeting. The May meeting needs to be dedicated to developing the 2012 Report to the President.

Carol Wheeler suggested that Peter Berns' idea might become part of the 2012 Report.

Liz Weintraub agreed with Carol Quirk. Since time is running out to have an impact on the President's policy before the election, PCPID needs to concentrate on the report.

Julie felt that it should not be a problem to take twenty minutes during the May 2012 Meeting to talk about the Executive Order.

Deborah asked when the Executive Order expires. The expiration date for the Executive Order is September 30, 2013. If PCPID wants to request that the Executive Order be changed, it would be timely to do it sooner rather than later. It would be good to request the change at the same time as the 50th Anniversary, especially if the Committee wants to take a new approach. Discussing PCPID's roll may give the Committee some vitality towards the PCPID Report. Therefore, the sooner the discussion takes place, the better.

Laverdia suggested forming an Ad Hoc Group to address questions regarding the Executive Order. This would allow pre-planning in addition to an agenda item at the meeting.

Peter Berns will take the lead on the Ad Hoc Group related to the Executive Order. Peter Bell volunteered to assist with the Ad Hoc Group.

Lauren Potter left the call to board her plane.

Jim Brett shifted the subject of the call back to the chart and recommendations from the 1967 Report. He thanked PCPID Staff for their work on the Framework for the 2012 Report.

Sharon suggested that, since there is limited time on the conference call, individual member should send an email to staff with any specific comments about the chart produced by staff. In reviewing the chart,

Committee members have expressed a desire to share the evolution of thinking, rather than just sharing the event-based progress. The most fundamental shift since 1967 is attitudinal. The presumption of competence and the availability of opportunity for people with ID have greatly improved and developed since the Committee began. These shifts in thinking are related to the events that have taken place and vice versa, in a cyclical relationship. PCPID needs to decide how to best represent this change in thinking and attitude and which issues to focus on for the future.

Deborah Spitalnik pointed out that a framework for government policy was established prior to Johnson's creation of the Committee. That framework interjected the concerns of people with ID and their families into the fabric of government. Government involvement is very important to people with ID and needs to be protected from the current assaults on this idea.

Liz Weintraub stated that, in her opinion, the biggest change since the Committee's establishment is the leadership and self-advocate roles of people with ID. People with ID are now speaking for themselves.

Carol Quirk agreed with Liz Weintraub about the importance of self-advocacy. She also agreed with Deborah Spitalnik's suggestions in three categories: share the evolution of thinking, explain how the lives of people with ID have changed, and focus on future directions and necessary progress.

Micki Edelson asked if it would be possible to bring in examples of corporate leaders who have embraced the hiring of individuals with ID in their corporations.

Commissioner Lewis asked that members wait to choose speakers for the May meeting until after the discussion on the Report. This will allow PCPID to invite speakers that will contribute needed information on the Report topics.

Returning to the discussion, Commissioner Lewis stated that there seemed to be an interest in following Deborah Spitalnik's suggestions: focusing on the fundamental shift in thinking related to people with ID, including how those individuals think about themselves, and focusing on future directions.

Susana would like to highlight the contributions of people with ID and parents who fought for those changes.

Jack Brandt expressed his appreciation for the evolution of thinking, but thought PCPID should focus on and make recommendations around the future.

Sheryl White-Scott agreed with previous comments regarding the framework and with Jack Brandt's comments. She also pointed out the importance of considering the impact of some of the legislative and economic changes taking place and how those changes could dismantle some of the progress in this area. She added that weaving personal stories into the mix would be very illustrative.

Carol Quirk stated that the events that Sharon talked about could be in an appendix.

Commissioner Lewis asked whether the Committee was ready to propose the structure for the framework of the Report and make a decision. She inquired in which of the potential areas members would need additional information, background materials, and expert testimony to inform members about recommendations for the future. The Commissioner asked for someone to make a motion to move forward with the discussed changes, making the shift from a less event-based model for the 2012 Report to a model that focuses more on the evolution of thinking over the last fifty years.

After some discussion of the plan for the 2012 Report, Liz Weintraub made the requested motion, according to the Commissioner's previous explanation.

Deborah suggested incorporating a life-span perspective. Some topics worth considering are as follows: how changes in life expectancy affect people with ID; how aging affects people with ID; and what life will look like fifty years from now for people with ID.

Carol Quirk suggested that members address education issues, including early childhood education family and school-age issues. Supports and services are not yet available for people with ID in this phase of life.

Susana agreed. Meaningful inclusion for children with ID is not yet what it should be.

Peter Berns suggested looking at the impact of the charter school movement. Additionally, along the lines of the lifespan theme, a huge transition takes place for older adults when they transition from family homes to outside care because loved ones are no longer able to care for them. The Committee should address these issues.

Annette agreed with Carol Quirk. The concept of inclusion for young students with ID is not a reality in the school system.

Liz suggested that, when talking about education, employment also needs to be discussed. There is no expectation that people with ID will have careers.

Carl suggested talking about services for seniors. People are living longer and needing services longer as a result.

Jack Brandt agreed with Liz Weintraub. PCPID needs to talk more about economic self-sufficiency.

Liz Weintraub said that several of the people on the call had been involved with the Self-Advocacy Summits. At the summit in Hawaii, she learned that people with ID in Hawaii are still struggling much more than people in the mainland. She concluded that "lots of people just want real lives."

Ann Hardiman expressed her appreciation for Liz Weintraub's comment. She proposed that another focus needs to be on where people with ID live. Many people with ID do not live in their own homes with the supports they need, people they have chosen, and well-trained support staff. There are pockets of better situations and worse situations.

Peter Bell explained that, for an outsider, the policy, legislation, language, and other information related to the history of the ID community can be difficult to understand. There has to be a way to help the general public understand what kind of progress has been achieved in the last 50 years and what the future directions will be. Perhaps the Report could help that understanding. PCPID should direct its efforts towards people who are not deeply entrenched in the ID community.

Carol Quirk agreed with Peter Bell's comment. She also emphasized the importance of presenting the vision of self-advocates.

Carol Wheeler suggested that members transition to a discussion of what experts to invite to the May meeting. She would support the idea of bringing in someone to help with messaging and communication to people that do not deal with ID issue on a daily basis. Carol like the idea of Chairman Brett's national correspondent helping the Committee.

Carol Quirk suggested inviting the heads of self-advocacy organizations to present their current priorities.

Liz Weintraub liked Carol Quirk's idea. She also suggested that PCPID include the heads of organizations that deal with other disabilities besides ID.

Sharon said that there has been a wide range of discussion on the framework and general approach to the 2012 Report. The next step will be to focus in on which priorities and expertise would be most useful for the May meeting to help formulate priorities and recommendations. She suggested using one of the two days during the face-to-face meeting to hear from experts or panels of experts. The second day could be used for deliberating, decision making, and developing recommendations. Commissioner Lewis recounted some of the points that had been discussed by members:

It might be helpful to bring in individuals from the self-advocacy community with different disability perspectives, including people with ID.

Micki Edelsohn talked about bringing in corporate representatives who are working on employment issues.

Members also talked about a list of potential topic areas, ranging from education to employment to aging, to self-sufficiency, transition from the family home, looking at where people with ID live, the professionalism of the direct care work force, and so on.

Commissioner Lewis inquired what expertise might be most useful, being mindful of the limited time available.

Deborah suggested that the committee needs to hear where long-term services and supports are going in terms of funding and CMS. That is the underpinning of the state service systems.

Peter Berns stated that, from a person centered approach, the ultimate question relates to the quality of life currently experienced by people with ID. He suggested bringing in someone like Jim Gardner from CQL or someone from National Core Indicators, who would be knowledgeable or have access to information on this question. There may be others who can contribute as well. Mr. Berns also suggested tapping aggregate data on self-advocacy that show quality of life for people with ID/DD.

Carol Quirk liked Peter Berns' idea. She recommended Melodee Muskgrove from OSEP as a guest. She would have a great deal to offer on the topic of education, including knowledge of the issues currently facing the U.S. Government in the state and local implementation of IDEA and data on disproportionality and over-identification of minority students with ID.

Clay Boatright agreed with Peter Berns thought about getting a good diagnosis of the best ideas and practices developed for people with ID. These should come from organizations of all sizes, both inside and outside of government funding. Government funding may not be as available in the future as it has been in the past. PCPID should look for options that give people with ID higher quality of life and more opportunity without being government funded.

Carol Wheeler agreed with Micki Edelsohn's idea of bringing in people from the corporate community who have made employment for people with ID work in their own companies. She suggested including a representative sample from different sectors, including small businesses and the Federal Government.

Chairman Brett offered to share a list of people from mid-sized companies that have employed people with ID.

Since the list of desired participants is getting long, Deborah suggested thinking about two approaches. First, she recommended giving presenters a structure their presentation topics, possibly a series of questions

or prompts. Second, Committee members may consider interviewing experts outside of the meeting in order to get the full range of perspectives. PCPID has other ways of gathering data beyond the meeting.

Commissioner Lewis agreed. If the Committee wants specific data, staff may be able to provide what is needed.

Julie Petty expressed her desire to include only employers with integrated employment for individuals with ID as speakers for the May meeting.

Deborah Spitalnik pointed out that the Department of Labor has data on employment for people with ID. That may provide information about the kinds of jobs and wages available. Data is also available related to education nationally and long-term care (where people are living and the types of settings). Perhaps Charlie Lakin might be willing to do some of that review and analysis for the Committee.

Jack Brandt said that data needs to be gathered from various sources because there is no central database.

Liz Weintraub heard from a panel of Wal-Mart representatives who talked about employment for people with ID. They hire a person with a disability for a specific job that they can do, not for the sake of hiring someone with a disability.

Jim asked Sharon how to move forward.

PCPID Staff will begin to pull together data regarding long term services and supports, education, and employment. Staff will follow up with specific members that have talked about those issues to find out the kinds of questions they would like to see answered before we put inquiries out to PCPID's federal partners. PCPID will work with Charlie Lakin, colleagues at the department of Labor, and colleagues in the ADD projects to pull together answers to any specific questions. Some of the substantial data resources that staff pulled together for the last report can be reused. She expressed a desire to keep this process from becoming overly complex.

Members will email specific questions that they would like answered with data to MJ. Staff will answer those questions, follow up with members who have discussed these topics on the call, and put together questions related to data for PCPID's federal partners. Included in that, PCPID would like information on employment for people with ID in the federal government.

Commissioner Lewis expressed her concern that people who have been hired by the federal government may not be broken down into specific types of disabilities. Rather, there may only be information about the total number of people who have been through Schedule A Authority. This may not meet the needs of the Committee.

Carol Wheeler suggested that anecdotal information about people with ID in the federal workforce might still be useful.

Laverdia Roach requested that input be sent from members to staff by next Friday. The deadline was confirmed.

Sharon said that, in terms of determining experts, what she'd heard is a suggestion to bring individuals in to talk about the following:

- 1) **Quality of Life.** The Committee discussed having experts speak about general quality of life and data related to quality of life. That panel might include Jim Gardner from CQL and Chas Mosley

from the National Core Indicators Project. Invitees should be people who can walk members through what are people with ID are saying about the satisfaction in their lives in multiple areas.

Deborah suggested looking at the particular elements contributing to quality of life in addition to looking at the data. She is concerned that the services supporting quality of life are at risk.

2) **Employment.** There was an interest in looking at employment from a multitude of employer perspectives, including organizations of various sizes and from sectors. The goal would be to hear from employers who have successfully employed people with ID in integrated environments with competitive wages and benefits. PCPID will look at which public policies, environmental elements, or economic factors are benefits or barriers in achieving this kind of employment. The different employer perspectives should include large corporations, small businesses, and government. A federal government speaker may be asked to talk about higher trends since the Executive Order related to employment for people with disabilities. Staff will need to work with members to sift through the suggestions and decide how to represent this issue and which experts to invite to the meeting.

3) **Education.** Members talked about inviting federal staff from the Office of Special Education Policy. Specific topics of interest included disparity and outcome data. Commissioner Lewis suggested asking Melodee Muskgrove to talk about both IDEA policy and the direction of the Department of Education in suspending their monitoring visits in order to examine the indicators and what compliance should mean under IDEA. She also suggested inviting Rosaline Ali, the Assistant Secretary for Civil Rights at the Department of Education. Her office is responsible for data on disproportionality, access, seclusion, restraint, corporal punishment and general human and civil rights issues for students in the schools. Susana Ramirez expressed her support for Sharon's suggestions.

Deborah Spitalnik suggested looking at post-secondary education, and the Commissioner expressed her support for that idea.

4) **The Future Directions of Long Term Services and Supports.** Another point of discussion has been on where long term services and supports are going, from both a Medicaid and Social Security perspective. CMS was mentioned as a possible expert on this issue. Many questions exist about where these services are headed, and much of the outcomes for services are yet to be determined. This is an opportunity to make recommendations about what Committee members would like to see happen with long term services and supports.

Sharon asked what information Committee members would need to setting forward recommendations. If they could design a system for the future, what would they select?

Deborah asked for the perspective of CMS and a state government. She suggested comparing a state government that has put long-term services and supports into a managed care approach and one that has not. The way the CMS policy plays out at a state level affects the lives of people with ID.

Another Committee member suggested looking at a for-profit company that does managed care at a state level. He also asked whether there is there an international perspective that would demonstrate the different ways that other companies deal with these issues.

Ann Hardiman explained her concerns about long term care, whether all the pieces (e.g. resources, workforce, transportation, medical professionals, etc.) are available in the community. If there are no resources in the community, it leads to more congregate living.

5) Hear From Self-Advocacy Leaders and Constituency Group Representatives.

Carol Wheeler reminded members that bringing in a messaging expert was also discussed.

Allison Hillman asked whether there would be another in-person meeting before launching the report. Commissioner Lewis confirmed that there would be. However, the members may not want to wait until that meeting to finish the Report. Sharon would like that last meeting to be celebratory and would potentially like to meet at the White House. If the Report is to be completed by the end of the calendar year and the fiscal year, it is important to be able to have hear the experts and make decisions at the May meeting.

Allison Hillman suggested waiting until the content is more developed to bring in the messaging expert come. Carol Wheeler pointed out that a communications expert might provide advice that might affect the content of the Report.

Deborah Spitalnik suggested that the first day of the May meeting be set aside for content immersion and information sharing. The second day would be for messaging and organizing the concepts from the first day. The Chairman's expert could lead the discussion on the second day.

An unidentified member reminded the Committee about the proposal to look at PCPID's role and maximize PCPID's impact as a Committee.

Liz asked whether there would be a facilitator for creating the upcoming report. Sharon said, if the Committee wanted one, they could discuss it. However, there are limited resources available to PCPID.

Commissioner Lewis pointed out that it would be difficult to cover all five of the proposed topics on the first day of the meeting. She suggested prioritizing the topics down to three or four.

Laverdia Roach suggested using conference calling to address issues related to the charter, the prioritizing of recommendations for the Report, and the planning of the 50th Anniversary.

Deborah Spitalnik emphasized the importance of working on recommendations as a Committee. She proposed that members recast their discussion about the role of PCPID and the charter once they have seen what comes out of the in-person meeting in May. Carol Quirk agreed with Deborah Spitalnik that the limited time should be used to create the Report.

Carol Wheeler asked whether the PCPID members would be allowed to meet for longer than the business day when all the members are in DC for the face-to-face meeting. The Commissioner answered that meetings need to be transcribed, and out of consideration for individuals with disabilities and health conditions, PCPID will not hold formal committee business beyond the business day. Members may meet informally after hours.

Sharon strongly urged Committee members to limit the topics to three or four items for the first day of the May meeting. Three topics would allow two hours per topic for expert presentations and discussion; four topics would allow an hour and a half.

Carol Quirk suggested that the speaker for quality of life indicators be put on a panel about another topic. A panel of self-advocates needs to be included. Deborah Spitalnik suggested integrating quality of life into a

discussion about long-term supports. The CQL and National Core Indicators datasets are data sets about long-term supports. Ann Hardiman and Liz Weintraub agreed.

Peter Berns disagreed. The datasets about quality of life related to all aspects of life, not just long-term support. He suggested keeping the five topics discussed, extending them into the second day, and postponing a discussion of the role of PCPID. When information gets put into silos, the richness and understanding of individual circumstances gets lost.

Deborah Spitalnik explained that, in her view, less material is worthwhile because it allows for more Committee interaction, which allows members to work through the information together and develop a shared vision.

Peter Berns agreed that Committee interaction is important, but felt that it was also important to inform that discussion with evidence-based information about quality of life.

The Committee voted on how to conduct the PCPID May Meeting:

Option A: PCPID will keep all five topics, make them a priority, and spread the discussion of the topics over both days of the face-to-face meeting.

Option B: PCPID will keep the discussion topics to first day, cut them down from five topics to three or four, and focus on discussion and deliberation of these issues on the second day.

A roll call vote was conducted. Seven Committee members voted for option A and ten voted for option B. PCPID will move ahead with option B.

Staff will prepare and distribute an email ballot for PCPID members to vote on which of the five areas discussed should be discussed during the May meeting. Members will return the ballot to PCPID staff via email or fax by close of business on Tuesday, April 10, 2012.

Carol wheeler suggested including a self advocate on each of the panels.

Ann Hardiman made the motion to adjourn. Susana Ramirez seconded the motion. The meeting was adjourned.