



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

~Minutes~

August 16, 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 Edelson
Ann Hardiman
Alison A. Hillman de Velasquez
Carl M. La Mell
Carol Quirk
Susana Ramirez
Deborah M. Spitalnik, Ph.D.
Lillian Sugarman

Liz Weintraub
Carol Wheeler
Sheryl White-Scott, M.D.
Mark Gross (US Department of Justice)
William D. Falsey (US Department of the Interior)
Michael Caliendo (US Department of Transportation)
Richard Balkus (US Social Security Administration)
Mary Kay Mauren (Equal Employment Opportunity Commission)

Public Participants

Audrey Busch
Margo Izzo

Scott Lissner
Tom Thompson

ADD-PCPID Staff

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

Sheila Whittaker
Genevieve Swift
Aaron Wiggins

~ SUMMARY OF PROCEEDINGS ~

Greetings, Call to Order and Agenda Review

Sharon Lewis, ADD Commissioner, PCPID Designated Federal Official

Jim Brett, PCPID Chair

Dr. Deborah Spitalnik, Co-Chair of the Working Group on Report Topic and Themes

Peter Berns, Co-Chair of the Working group on Report Topic and Themes

Commissioner Sharon Lewis welcomed Committee members and called the meeting to order. Ms. Lewis reminded members that an agenda for the day's conference call was sent out by staff during the previous week. She turned the meeting over to Chairman James Brett.

Chairman Brett began by commending Ms. Allison Hillman de Velasquez and Ms. Carol Quirk for leading their respective Working Groups. He also thanked Dr. Deborah Spitalnik and Mr. Peter Berns for their work and support as co-chairs of the PCPID Subcommittee on the Report Topic and Themes. He then turned the meeting over to Dr. Spitalnik and Mr. Berns.

Dr. Spitalnik briefly reviewed the meeting agenda. She asked Commissioner Lewis to indicate the time that she would like to give an overview of the Budget Control Act and its impact on the work of the Committee. Commissioner Lewis deferred to the co-chairs, as the leaders of the discussion, to set the time. Dr. Spitalnik stated it would be best to begin with the Commissioner's overview so that the Committee may make an informed decision about how to progress on the 2011 Report to the President.

Overview of the Budget Control Act

Commissioner Sharon Lewis

Commissioner Lewis pointed out that the impact of the Budget Control Act, and the Super Committee, was unclear since the work of the Super Committee had recently begun. She noted that the legislation was unprecedented, as it addresses the debt ceiling and establishes a Super Committee to address reduction of the budget deficit for the next decade. She stated that certain financial targets, which the Appropriations Committee must reach, are significantly lower than the President's proposed budget for FY2012. Commissioner Lewis outlined how the first round of budget cuts were to be equally divided between domestic/discretionary and security spending. This equal distribution would only be required during the first round, and could be adjusted in future rounds. She added that mandatory spending such as Medicaid, Social Security and other programs related to eradication of poverty are protected from the first round of cuts. She stated that the responsibility of the Super Committee is to set a plan, by November 23, 2011, that will make at least \$1.2 trillion worth of cuts to the budget deficit. If the Super Committee can produce a plan that is supported by seven of its member by the November 23rd deadline, the plan will immediately go through a streamlined process to the House of Representatives and the Senate for up-or-down voting, without the opportunity for members of Congress to make additional amendments. If the legislation is passed by both the House and the Senate, then it will go to the President for signing. The Commissioner added that, should the plan designed by the

Super Committee fail, the legislation has a built-in fail-safe policy that will enact budget cuts across-the-board beginning in January 2013.

Chairman Brett stated that, from his understanding, discretionary programs would be cut by \$44 billion in the first year. Commissioner Lewis clarified that it would be \$34 billion in discretionary program cuts because of savings in Pell grants. Mr. Brett asked if the Super Committee could make cuts to Medicaid and Medicare. Commissioner Lewis replied that the Super Committee had a variety of options open to it which include cuts to entitlement programs like Medicaid and Medicare as well as tax revenue options. Chairman Brett stated that this was an important factor for Committee members to remember, if decision is made to pursue the topic of ACA/Medicaid for the 2011 Report.

Dr. Spitalnik clarified that Medicaid/Medicare are entitlement programs, while programs from the Administration for Developmental Disabilities (ADD) are discretionary programs. Commissioner Lewis explained that discretionary programs are all programs that are funded by grants, including not only ADD but also programs related to education (both IDEA and ESEA), housing, and employment. Funding for these programs is determined by the appropriation bills approved by Congress. Medicaid, Medicare, Social Security and other entitlement programs are mandatory programs for which overall funding is determined by enrollment of eligible individuals and state take-up. In order to achieve the necessary cuts, the Super Committee will determine the make-up of the appropriation bills for the next 10 years. She added that the degree of specificity in how these cuts are achieved may be determined by Congress.

Ms. Elizabeth Weintraub asked whether poverty programs could be cut. Commissioner Lewis clarified that the legislation protects certain entitlement programs from the first round of cuts only. After this first round of cuts, the Super Committee is allowed to make cuts to these programs. If the Super Committee's proposal is not passed, however, the protected low-income entitlement programs will not be affected by the automatic, across-the-board cuts. The only exception will be Medicare, which could be cut up to 2% in provider rates.

Chairman Brett asked which process would protect more programs for people with intellectual disabilities from budget cuts. Commissioner Lewis replied that Social Security, Medicaid and Medicare may be more protected under across-the-board cuts. Dr. Spitalnik added that these programs would not be as protected, functionally, because states could potentially cutback on optional services under Medicaid as they provide about half of the funding for these programs. Commissioner Lewis elaborated that Medicaid maintenance of effort as established under the ACA applies to eligibility and not services, which would allow states to make the cuts mentioned by Dr. Spitalnik.

Ms. Weintraub asked Committee members advice regarding what she should recommend to her fellow self-advocates. Commissioner Lewis suggested that self-advocates determine the most important services for people with intellectual disabilities, as there may not be enough money for everything.

Report to the President – Topic, Selection and Composition Process All Members

Dr. Spitalnik recommended, in light of the Budget Control Act, a merger of the two Working Group topics of Employment and the Affordable Care Act (ACA)/Medicare. This will allow the Committee to demonstrate why programs related to these two subjects areas are important for people with intellectual disabilities, and need to be protected from excessive budget cuts.

Ms. Quirk and Ms. Hillman de Velasquez asked if the 2011 Report could have an impact on the decisions of the Super Committee. Mr. Berns suggested that, if it was within the role of the Committee, members should attempt to impact these decisions. Commissioner Lewis replied that, through its mandate, the Committee has the ability to generate communications to the President and the executive branch. She asked Ms. Laverdia Roach if there was historical precedence of the Committee directing a letter to Congress without going through the President. Ms. Roach replied that this had not been attempted in the past. Commissioner Lewis stated that she would check with the Office of the General Counsel to determine if this was something that the PCPID staff could legally support. Ms. Carol Wheeler suggested, as an alternative, sending a letter to the President that could be made public, noting that this will allow self-advocates and their organizations to use such a letter to support their own correspondence to Congress. Dr. Spitalnik agreed with this suggestion and added that the Committee should avoid the legal dispute that could arise from sending a letter directly to Congress. Chairman Brett stated that, from his understanding, the Committee was mandated to educate the President and the executive branch, but not the legislative branch. Dr. Spitalnik explained how past Committees were respected in the field as a voice to elevate issues important for people with intellectual disabilities. Mr. Clay Boatright suggested that members focus on the 2011 Report to the President, with the understanding that this document will be viewed by the public and, possibly, members of Congress.

Dr. Spitalnik asked if members would like to accelerate their timeline in order to produce a Report before the November 23rd Congressional deadline. Mr. Berns replied that the Committee needed to plan for a mid-October deadline if members decided to include the budget cut discussions. He summarized the previously expressed idea from members to demonstrate, in a report, the impact federal programs have on the lives of people with intellectual disabilities and why it is important that these programs continue receiving funding. He suggested using a portion of the September 26-27, 2011 Committee Meeting as a public hearing. Ms. Weintraub supported this idea and stated that it was important for self-advocates to be heard, as these decisions will profoundly impact their lives. Dr. Spitalnik suggested using a different format to portray the voice of self-advocates. Ms. Hillman de Velasquez asked if this format will be used this year or next year. Dr. Spitalnik replied that the format for this year will be to explicitly demonstrate how entitlement and discretionary programs are essential to the lives of people with intellectual disabilities. Ms. Hillman de Velasquez agreed with this suggestion and recommended that members begin working on this before the September meeting, considering the proximity of an October deadline. Ms. Roach suggested a one to two hour open forum at the beginning of the PCPID September meeting to facilitate more public input. Ms. Hillman de

Velasquez expressed concern with waiting until the end of September for such an open forum. Ms. Roach clarified that this open forum would be in addition to other forms of information gathering. Dr. Spitalnik recommended a more structured format than an open forum because one to two hours is a very small allotment of time, and an open forum would require speakers to be physically present at the meeting.

Ms. Wheeler asked if Committee meetings have received press coverage in the past. Ms. Roach replied in the affirmative and stated that she and Commissioner Lewis could speak to the Director of the Office of Public Affairs about arranging press coverage for the September meeting.

Ms. Lillian Sugarman asked if members could conduct personal interviews with people with intellectual disabilities and bring the results to the September meeting. She suggested that some members focus on the broader topics of how loss of certain programs will affect this population in general, while other members focus on conducting interviews. Ms. Weintraub suggested the National Disability Repository's report on closing workshops as a resource for stories about people with intellectual disabilities and employment. Ms. Susana Ramirez agreed with the importance of having personal stories, but in conjunction there should also be work on the substantive issues to supplement the interviews. Mr. Carl La Mell stated that it is important to use the September meeting to finalize the collected work.

Mr. Berns asked if there was consensus to refocus the 2011 Report to the President on demonstrating the impact of entitlement and discretionary programs on the lives of people with intellectual disabilities. Several members agreed with this redirection and no objections were raised.

Dr. Spitalnik asked if it was possible to gain more positive attention by demonstrating why the programs matter instead of simply arguing against cutting federal funds. Ms. Weintraub replied that demonstrating the importance was essential as she, her family, and her friends would experience great difficulty without these programs. Ms. Micki Edelson recommended including the perspectives of companies that are able to successfully employ people with intellectual disabilities.

Chairman Brett suggested contacting the office of Senator Tom Harkin [Iowa] to gain an idea of what kinds of stories and information will have the greatest impact on the budget cut discussions. He agreed with the suggestion to portray the perspectives of employers. He also recommended a focus on moving people with intellectual disabilities out of daycare centers and sheltered workshops into competitive employment. Dr. Annette McKenzie Anderson suggested using employment as a more focused subject, through which the Committee can demonstrate why these programs are beneficial. Ms. Ann Hardiman suggested using the interviews to "put a face on" the individuals that Medicaid helps for the benefit of those who do not understand why these programs are necessary. Dr. Spitalnik reiterated the concept of a merger between the two topics (Employment and ACA/Medicaid) in the 2011 Report, in order to fight against the vilification of these programs.

Mr. Berns suggested focusing the report thematically, in order to touch on numerous issues important to people with intellectual disabilities. He recommended having panels at the September meeting that focus on each topic (employment, community living, healthcare). Mr. Berns speculated that, after the meetings, members could use the results of the panel presentations to supplement the work prepared beforehand. Dr. Spitalnik emphasized the time constraints and recommended that members begin finding information and drafting sections of the Report in the coming month. Mr. Berns responded that the September meeting will still present opportunity for media coverage of the issues. He suggested having one group focus on the outline for the Report and another group work on the agenda for the September meeting. Ms. Quirk added a third group that would conduct interviews. Dr. Spitalnik recommended keeping the current Working Groups intact, as they have already started collecting information that would detail how the programs work for people with intellectual disabilities. She stated that she and Mr. Berns could work on the overall structure of the Report.

Ms. Quirk stated that, although members appeared to be in consensus on the process, the exact focus of the Report was still unclear. Dr. Spitalnik emphasized the importance of monitoring both employment and Medicaid, as “the entire structure of community living at the state level is predicated on Medicaid waiver services.” Ms. Quirk recommended prioritizing the work that can be accomplished before the September meeting. She stated that, while Medicaid appeared to be the overarching theme, there are issues with employment that are outside the realm of Medicaid, such as the type of employment that people with intellectual disabilities are receiving. Mr. Richard Balkus suggested focusing the first report on programs that contribute to employment outcomes, and addressing Medicaid from this perspective. He explained that there was concern within the U.S. Social Security Administration about programs like the *Ticket to Work*.

Dr. Spitalnik suggested returning to the initial focus of the second, larger Report and the Executive Order, which was full participation and community life. She stated that the defining element of this focus for adults would be employment, but at other stages of life, there are other discretionary programs that are also crucial. She recommended using Medicaid/Medicare as the overarching social structure, which is required for the facilitation of full community participation. Ms. Edelson asked if members should stay within the Working Groups that have already been formed and begin delving deeper by finding personal stories. Dr. White-Scott responded that this was a good idea, and members should stay within their Working Groups.

Mr. Berns reiterated that he and Dr. Spitalnik would work on the overall outline of the Report while the two Working Groups continue working on gathering information and personal stories related to their topic. He added that he and Dr. Spitalnik will investigate other areas outside of the topics of employment and Medicaid that should also be included in the Committee’s Report to the President. He offered education and housing as examples of these areas.

Mr. Boatright summarized the process, as outlined in the call, and recommended making a broad-based announcement, through various media resources, for the September meeting, which would allow for public commentary. These comments would be used to supplement the fact-finding of the Working Groups. Dr. Spitalnik advised caution against a broad-based announcement, as time was limited. Mr. Boatright clarified that the public input gathered from

the September meeting would be from speakers invited by the Committee. Mr. Balkus recommended targeting people with intellectual disabilities and their families as speakers for the September meeting, in order to gather success stories through utilization of the endangered programs. Ms. Weintraub and Ms. Edelson offered their assistance in finding the suggested speakers and success stories.

Ms. Wheeler inquired about the logistics and deadlines for accomplishing the aforementioned tasks. Ms. Spitalnik responded that it may be possible to look at the lives of several people with intellectual disabilities and dissect the programs and support services needed for them to arrive at their current place in life. Ms. Sugarman and Ms. Wheeler suggested designing a set of questions that members could use in the interviews in order to increase consistency. Ms. Sugarman asked if there should be a list of people, who will be responsible for gathering interviews. Dr. Spitalnik replied that all of the members should attempt to gather stories, if possible, and a decision of which stories to include could be made at a later date. Ms. Weintraub recommended how the programs increase the happiness of people with intellectual disabilities. Dr. Spitalnik reiterated the idea of bringing self-advocates and their families to the September meeting.. Chairman Brett suggested inviting a representative from the Office of Management and Budget to give a presentation on the act and how it will impact the lives of People with intellectual disabilities. Ms. Roach agreed to pursue this and brought to the members attention information that she has emailed to them about the Budget Control Act and its potential impact on people with intellectual disabilities.

Mr. Berns stated that the first step is to design an outline and structure for the 2011 Report. Chairman Brett asked if Mr. Berns and Dr. Spitalnik had a timeframe for completing such an outline and structure. Dr. Spitalnik responded that they could try to have the outline and structure of the Report completed by early next week (August 22, 2011).

Chairman Brett reminded members of the reception at the residence of Ms. Wheeler. Ms. Wheeler explained that the attire for the event would be casual. Ms. Weintraub asked if Ms. Wheeler's home was Metro accessible. Ms. Wheeler responded that it was not but she would be happy to make transportation arrangements if necessary, and asked that members contact her with any such issues.

Chairman Brett asked for a motion to adjourn. Ms. Weintraub voiced the motion, which was approved by several members of the Committee, and Chairman Brett adjourned the meeting.

ACTION ITEMS:

Committee Members:

- 1) Inform staff of self-advocates who should be invited to the September face-to-face meeting as speakers/presenters.
- 2) Conduct interviews with people with intellectual disabilities regarding the effects of entitlement and discretionary programs on their lives and the difficulties that could arise from the funding cuts of the Budget Control Act.

Co-Chairs of Subcommittee:

- 1) Develop the proposed outline and structure for the 2011 Report to the President, with subheadings for potential themes and topics.
- 2) Research areas beyond employment and the Affordable Care Act/Medicaid that should be added to the 2011 Report.

Working Groups:

- 1) Continue researching information on how entitlement and discretionary programs, within the Working Group's chosen topic, related to people with intellectual disabilities.
- 2) Compile success stories of people with intellectual disabilities who have been impacted by entitlement and discretionary programs.

PCPID Staff:

- 1) Convert the meeting recording into minutes.
- 2) Continue providing support to Working Groups in their pursuit of information related to *Employment* and *ACA/Medicaid*.
- 3) Contact the Office of Public Affairs about the possibility of media coverage for the September 26-27, 2011 Committee Meeting.
- 4) Contact the Office of Management and Budget, to request recommendation of a speaker to present an overview of the Budget Control Act and its impact on people with intellectual disabilities to present at the September Committee Meeting.