



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

Committee Meeting
August 3-4, 2015
~Draft Minutes~

Citizen Members

Julie Petty, Chair

Susan Axelrod

Peter Berns

Jack Martin Brandt

Jim Brett

Kenneth Capone

Micah Fialka-Feldman (via telephone)

Dan Habib

Zachary Holler (via telephone)

Stacey Milbern (via telephone)

Lisa M. Pugh

Michelle "Sheli" Reynolds, PhD (via
telephone)

Deborah Spitalnik, PhD

Mike Strautmanis (via telephone)

Ricardo T. Thornton, Sr.

Elizabeth Weintraub

Sheryl White-Scott, MD

Betty Williams

Ex officio Members and Representatives

Tinisha Agramonte

Representing the Honorable Penny Pritzker
Secretary, U.S. Department of Commerce

Julie Clark for Jennifer Sheehy

Representing the Honorable Thomas Perez
Secretary, U.S. Department of Labor

Mary Pletcher (via telephone)

Representing the Honorable Sally Jewell
Secretary, U.S. Department of the Interior

Sharon Lewis

Representing the Honorable Sylvia Burwell
Secretary, U.S. Department of Health and
Human Services

Jeanine M. Lafratta for Michelle Aronowitz
Representing the Honorable Julián Castro
Secretary, U.S. Department of Housing and
Urban Development

Howard Caro-Lopez, PhD for Yvette Rivera
Representing the Honorable Anthony Foxx
Secretary, U.S. Department of
Transportation

Sue Swenson

Representing the Honorable Arne Duncan
Secretary, U.S. Department of Education

Margaret Schaefer for Brian Parsons
Representing the Honorable Jeh Johnson
Secretary, U.S. Department of Homeland
Security

Stephanie Enyart
Representing the Honorable Wendy Spencer
CEO, Corporation for National and
Community Service

Mary Kay Mauren
Representing the Honorable Jenny R. Yang
Chair, Equal Employment Opportunity
Commission

Leola Brooks (via telephone)
Representing the Honorable Carolyn Colvin
Commissioner, U.S. Social Security
Administration

Gerrie Hawkins, PhD for Gary Blumenthal
Representing the Honorable Jeff Rosen
Chair, National Council on Disability

Special Guests and Presenters

Glinda Foster Hill
Education Program Specialist
Office of Special Education Programs, U.S. Department of Education

Loretta Hobbs, PhD
PCPID Consultant

David O'Hara, PhD (Presenter)
CEO, Westchester Institute for Human Development
Valhalla, New York

The Administration on Intellectual and Developmental Disabilities (AIDD) - PCPID Staff

Aaron Bishop, MSSW
Commissioner, Administration on
Disabilities and PCPID Designated
Federal Officer (DFO)

Madjid "MJ" Karimi, PhD, CPH
PCPID Team Lead

Ophelia McLain, DHA
Director, AIDD Office of Innovation

Sheila Whittaker
PCPID Program Assistant

Meeting Proceedings

DAY ONE (August 3, 2015)

Greetings, Call to Order, and Introduction of PCPID Chair

Aaron Bishop, Commissioner, Administration on Disabilities
PCPID Designated Federal Officer (DFO)

Commissioner Aaron Bishop welcomed participants and thanked PCPID members for joining the meeting. He stated that, throughout the meeting, members are scheduled to cast their voting ballots (i.e., when consensus is reached) and discuss the potential topics for the PCPID 2016 Report to the President (RTP). He added that the sign language interpreters, as well as the court reporter, have requested that when speaking during the meeting, members should state their names for record keeping purposes. He turned the meeting over to the PCPID Chairwoman, Ms. Julie Petty.

Opening Remarks, Meeting Overview, and Introduction of PCPID Members

Julie Petty, PCPID Chair

The PCPID Chair, Ms. Julie Petty, welcomed participants and called the meeting to order. She thanked the members and staff for their teamwork in preparing the PCPID 2015 RTP. She also thanked participants and requested all members to introduce themselves and, to identify their affiliations with the Committee. This was done in a “round robin” format.

Due to technical difficulty with the phone lines, members were asked to take a five minutes break. After the break, Commissioner Bishop resumed the meeting and stated that Dr. David O’Hara, CEO of the Westchester Institute for Human Development, has been invited to provide a presentation on the “multimedia” production of the 2015 RTP during the second day of the meeting. He, then, turned the meeting over to Chairwoman Petty for further discussions and presentation of the 2015 RTP.

Approval of Agenda and Minutes (May 11, 2015)

PCPID Chair

Chairwoman Petty made a motion to approve the minutes of the PCPID May 11, 2015 Virtual Meeting. Dr. Deborah Spitalnik abstained. Mr. Jim Brett and Mr. Ricardo Thornton seconded the motion to approve the minutes of the PCPID May 11, 2015 Webinar. The Committee voted to accept the minutes as well as the meeting agenda.

Presentation of the 2015 Report to the President

PCPID Chair, DFO, and Members

Chairwoman Petty shared with the members that the self-advocate members of the Committee received instructions by her to present the contents and key recommendations of the 2015 RTP in the following four focus areas: 1) Elementary, Secondary, and Post-Secondary Education;

2) Community Living; 3) Employment and Economic Well-Being; and 4) Health and Wellness.

She identified the goals of the PCPID 2015 RTP as to increase:

1. The cognitive accessibility of technology that is part of the fabric of everyday lives and strengthen federal policies to ensure that people with ID have equal access to everyday technology, and
2. the availability, quality, and affordability of cognitive support technologies through policies, practices, development, and research.

The PCPID Chair, then, asked the presenters (Liz Weintraub, Ken Capone, Jack Martin Brandt, and Betty Williams) to start their presentations.

***Liz Weintraub, Elementary, Secondary, and Post-Secondary Education
PCPID Citizen Member***

Ms. Weintraub began her presentation by asking the following questions: How can technology be used more effectively to make educational materials cognitively accessible? How can we make accessible technology available to learners with intellectual disabilities (ID), both in inclusive and non-inclusive settings, given that nearly 83% of all students with ID are not yet fully included in general educational classrooms? Ms. Weintraub, then, stated that the Committee highlighted several key recommendations in the Report in order to address these questions. These recommendations are as follows:

- Offices responsible for the Elementary and Secondary Education Act (ESEA), Individuals with Disabilities Education Act (IDEA), Higher Education Opportunity Act (HEOA), and other federal programs are urged to require accessibility in all educational technology they support.
- The offices that administer ESEA, IDEA, HEOA, and other federal laws should include accessibility requirements in any online learning tools or systems whose development they support, and encourage others to do so wherever permissible by law.
- The U.S. Department of Education (ED) should issue guidance recommending that all educational curricula purchased by schools (kindergarten through higher education) meet current industry standards for accessibility including cognitive accessibility.
- Federal offices should support improvements in copyright law and practice wherever possible so that people with ID can access free electronic books for individuals with a print disability.
- The U.S. should ratify the Marrakesh Treaty to Facilitate Access to Published Works for Persons Who are Blind, Visually Impaired or Otherwise Print Disabled. The treaty will allow sharing of accessible materials, for use by members of the beneficiary groups, across international borders, thus increasing the number and supplies of materials

accessible to persons with disabilities. ED should offer data and other support toward achieving the goal of ratification wherever possible.

Ms. Weintraub thanked the “Education” Workgroup Members: Dan Habib (Workgroup Lead), Glinda Hill, Zach Holler, and Ricardo Thornton for their diligent effort to complete this section of the Report.

Ken Capone, Community Living
PCPID Citizen Member

Mr. Ken Capone started his presentation on the Community Living section of the 2015 RTP. He raised the question: How should the requisite research and funding be acquired to achieve advances in accessible technology that will result in greater independent living options and full citizenship benefits for people with ID? Mr. Capone stated that the Committee highlighted some key recommendations in the Report in order to address this question. These recommendations are:

- The U.S. Department of Health and Human Services (HHS), Centers for Medicare and Medicaid Services (CMS) should consider whether States are utilizing technology to improve and expand access to integrated community living as one aspect of the settings compliance analysis under the new Home and Community-Based Services (HCBS) regulation.
- Federal agencies should research, fund, and create more technology applications (“apps”) which expand the independence and participation of people with ID in everyday living situations.
- Federal agencies should incentivize product developers to design software that is highly visual and customizable with verbal and non-verbal cues, and that contains real-time pictures and videos to orient and engage users with ID.

Mr. Capone acknowledged and thanked the “Community Living” Workgroup Members: Susan Axelrod, Gary Blumenthal, Yvette Rivera, Ricardo Thornton, & Liz Weintraub

Jack Martin Brandt, Employment and Economic Well-Being
PCPID Citizen Member

Mr. Jack Martin Brandt began his presentation by posing the following questions: How can people with ID obtain and more effectively use technology in employment and to ensure their economic well-being? How can federal agencies incentivize the technology industry and employers to develop, promote and use accessible technologies that increase employment opportunities and on-the-job success for people with ID? Mr. Brandt, then, stated that the Committee highlighted key recommendations in the Report in order to address these questions. These recommendations are:

- ED and HHS should provide guidance on the inclusion of mainstream, accessible information and communications technologies in the definition of “assistive technology” in federal education and vocational rehabilitation policy.
- ED and HHS’s National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) should provide additional information and resources to the state vocational rehabilitation programs on the use of technology and related technology services, as part of Individualized Plans for Employment (IPEs).
- HHS-NIDILRR and the U.S. Department of Labor (DOL) should continue funding research that specifically focuses on the use of technology to increase competitive, integrated employment outcomes for youth and adults with ID.
- The U.S. Department of Labor (DOL) should issue technical guidance to American Job Centers on the use of accessible technology in serving One-Stop customers (designed to provide a full range of assistance to job seekers under one roof) with ID. This guidance should advise contractors about best technology practices and resources to increase the hiring and employment of individuals with ID.

Mr. Brandt thanked the following members of the “PCPID Employment and Economic Well-being” for their support: Peter Berns, Leola Brooks, Julie Clark, Julie petty, and Yvette Rivera.

Betty Williams, Health and Wellness
PCPID Citizen Member

Ms. Betty Williams started her presentation on the “Health and Wellness” section of the 2015 RTP. She asked the following question: How can product developers, researchers, funders and others use widely available technology as a resource to increase the involvement of people with ID in their own health care and health care decision-making? She, then, stated that the Committee highlighted three (3) key recommendations in the Report in order to address these questions. These recommendations are as follows:

- As a part of the review and approval process for Medicaid State Plan Amendments and Waivers, HHS-CMS should require states to fund personal and mainstream technologies (including mobile devices) that can optimize participation of people with ID in their own health care and wellness.
- Technology should be used for ongoing training of health care professionals to increase their skills, knowledge and understanding of people with ID.
- Electronic records should be promoted and shared between health care systems and programs furnishing long-term services and supports to improve care for individuals with ID, and to provide longitudinal data for systems and budgetary planning.

Ms. Williams also acknowledged and thanked the following members of the PCPID Health and Wellness Workgroup: Dr. Deborah Spitalnik and Dr. Sheryl White-Scott (Co-Leads), Susan Axelrod, and Jim Brett.

Chairwoman Julie Petty and Commissioner Aaron Bishop, Overarching Recommendations

Chairwoman Petty and Commissioner Bishop presented to PCPID members, the following ten (10) overarching recommendations included in the Report for the President's consideration:

1. Recognize and affirm the equal rights of people with cognitive disabilities to technology and information access by adopting and embracing the *Declaration of the Rights of People with Cognitive Disabilities to Technology and Information Access*, among other things.
2. Adopt and incorporate into federal statute, policy and recommended practice definitions for the following:
 - **“Cognitively Accessible Technologies”** – Usability of technology by people with I/DD.
 - **“Cognitive Design”** – Ensure that mainstream technologies are designed for people with I/DD from the beginning and that the design includes their input. Cognitive Design must not only include design, but also access functions.
3. Ensure that technology is accessible, affordable, and widely available to people with intellectual and developmental disabilities who can benefit from it at home, in their communities, and at work.
4. Direct the U.S. Department of Education Office of Civil Rights to revisit the definitions of the terms “otherwise qualified” relative to eligibility for accommodations under Section 504 of the Rehabilitation Act and the Americans with Disabilities Act. The emerging benefits of supportive, assistive and also prosthetic technologies offer a significant extension of individual capabilities that were unavailable when these statutes were drafted.
5. Amend the functions of the U.S. Access Board (Section 502 of the Rehabilitation Act) to include the development of data standards to facilitate promotion of cognitive design and guidelines, incorporating solutions that include use of cognitively accessible technologies in businesses, communities, and the federal government.
6. Ensure that federal agencies interpret Section 508 of the Rehabilitation Act in a manner that creates cognitively accessible pathways to information, policies, and programs that are useful and available to people with ID.
7. Direct the U.S. Department of Justice to enforce the Americans with Disabilities Act so that public and private entities' services and programs that are available through electronic technology are readily accessible to people with ID.
8. Promote continued Research and Development funding and longitudinal testing of new cognitively accessible technologies, including speech-to-text technologies that increase the independence of people with ID. Request creation of a research agenda through the demonstration projects of the NIDILRR and the CMS.

9. Direct the U.S. Department of Education and U.S. Department of Health and Human Services to provide funding opportunities for the creation and support of an open access site (i.e., a repository of resources including codes), containing resources for developing accessible information and materials for people with cognitive disabilities.
10. Create federal incentives (e.g., tax credits) for the private sector to develop cognitively accessible technologies.

Discussion of the 2015 Report to the President

PCPID Chair, DFO, and Members

Dr. Sheryl White-Scott asked if the Committee has received concerns about the language of the first key recommendation in this section from the CMS. Chairwoman Petty responded, “Not yet.” Ms. Sharon Lewis, ACL Principal Deputy Administrator and Senior Disability Policy Advisor to HHS Secretary, suggested an amendment to the language of this particular recommendation, because CMS cannot “require” states to fund without a statutory change.

Dr. Deborah Spitalnik shared with the Committee that the focus of the Health and Wellness section was to highlight and make the benefits of the Affordable Care Act (ACA) accessible to people with ID. She suggested that the Committee Members review the Report one more time to ensure all recommendations are within the purview of PCPID and its executive order. Dr. Spitalnik added that some of the recommendations may give the impression that the Committee is asking the Congress to act, and that is not the scope of PCPID’s authority. She volunteered to review the Report and reword some of the recommendations, wherever applicable.

Ms. Weintraub asked if the recommendations could be included online through “Tuesday with Liz” videos to capture a broader audience of people with intellectual and developmental disabilities. Chairwoman Petty responded that this is part of the Report rollout and advertising that will be discussed in depth during the second day of the meeting. Mr. Dan Habib added that Benetech and Bookshare (online libraries) are currently working to make the Report accessible to people with disabilities. He added that Dr. O’Hara is scheduled to discuss how PCPID can incorporate the universally designed features in the Report on the second day of the meeting, so that people with different learning styles can access it easily.

Ms. Sue Swenson, Deputy Assistant Secretary, Office of Special Education and Rehabilitative Services (OSERS) at the U.S. Department of Education, thanked the Committee for their efforts in finalizing the PCPID 2015 RTP. She raised concerns that the federal government is not driving the development of new “apps,” and some recommendations in the Report are written in a format that they can be easily misinterpreted. Ms. Swenson added that two days before the anniversary of the American with Disabilities Act, OSERS created a \$ 20M grant opportunity for the automatic personalization project, which eventually help individuals with disabilities be able to pull down their personal preferences when using the web-enabled devices. She stated that the Department of Education won’t be able to clear the recommendations in the Report that are legislative. Ms. Swenson suggested that the Committee explore the ways to approve the PCPID Reports without the clearance process in the future. She, on behalf of the Department of Education, abstained from clearing the Report.

Ms. Susan Axelrod and Mr. Jack Brandt suggested adaptation of a consistent language in the Report, when referring to people with intellectual disabilities, versus individuals with cognitive disabilities. Ms. Jeanine Lafratta, from the U.S. Department of Housing and Urban Development (HUD), requested that the HUD's Housing Locator App (recently released) be added to the Report as an additional resource to people with ID and their families. Ms. Tinisha Agramonte, from the U.S. Department of Commerce, shared with the members that the Small Business Administration makes federal funds available to inventors of the innovative technologies. She added that the Report should include a question on how can the federal government incentivize, within the existing structure, the use of cognitive technologies.

Mr. Peter Berns asked if the Committee's staff is still accepting comments and suggestions on the PCPID 2015 RTP. Commissioner Bishop responded that staff is still accepting comments and suggestions because various *Ex officio* agencies are still in different stages of vetting and clearing process of the Report. He added that most of the suggestions and comments that staff has received thus far do not change the essence of the Report. He added that PCPID follows the "Clearance" guidelines, required by the Federal Advisory Committee Act of 1972. Mr. Berns thanked the Commissioner and asked if the first recommendation under the "Health and Wellness" section could be clarified more in depth. Dr. Spitalnik responded that that the Workgroup wanted to reaffirm that technology is instrumental in realizing the ACA. Technology is not driving the ACA; it is rather facilitate its access and implementation for people with ID.

Mr. Berns asked if he could discuss the first overarching recommendation regarding the *Declaration of the Rights of People with Cognitive Disabilities to Technology and Information Access*. He asked how federal government could adopt the Declaration. Ms. Swenson responded that perhaps if the word "adopting" be replaced with "embracing," that would make the recommendation sound more logical.

Ms. Lewis suggested that PCPID staff set up technical assistance calls with the Workgroup leads and *Ex officio* representatives to clarify the recommendations in question. She expressed belief that this will help to take the recommendations away from the directive to Congress and make them geared towards the Administration. Dr. Spitalnik explained that this could be captured by an introduction that recognizes these issues and volunteered to help shape the "Introduction" section of the Report. Dr. Gerrie Hawkins from the National Council on Disability suggested use of plain and easy-to-understand language, when editing the introduction of the Report. Chairwoman Petty agreed and encouraged the members to set up a deadline for the technical assistance calls and reshaping the "Introduction" section of the Report. Mr. Mike Strautmanis urged the leaders of the PCPID Workgroups, while making the editorial changes, to remember not only self-advocates, but also to keep in mind people who are interested in making impact on national policy.

Approval of the 2015 Report to the President and Voting Process PCPID Chair, DFO, and Members

PCPID Members decided to participate in technical assistance calls and edit the Report before casting their voting ballot. The process of voting for the approval of PCPID 2015 RTP was, therefore, postponed until Friday, August 21, 2015.

Introduce the Report Rollout Discussion (Preview Day-Two Discussion):

PCPID Chair and PCPID DFO

Chairwoman Petty shared with the members that Dr. David O'Hara, CEO of Westchester Institute for Human Development, is invited to provide a presentation on how to rollout the Report with different type of mediums and medias n the second day of the meeting.

Developing a Comprehensive List of Potential Topics for the 2016 Report to the President and Establishing New Workgroups

PCPID Chair and Members

Chairwoman Petty shared with the members that three (3) Workgroups will be formed to develop a comprehensive list of potential topics for the PCPID 2016 RTP. She encouraged the Committee to address the following questions, before the formation of the Workgroups:

- 1) What is important to people with ID and their families?
- 2) What are some of the general or specific topics for consideration of the Workgroups?

Dr. White-Scott asked when would be the deadline to complete the 2016 RTP, since a few of the members are scheduled to transition out of the Committee in May 2016. Commissioner Bishop responded that PCPID staff will collaborate with the Committee to prepare a good and solid draft of 2016 Report prior to May 2016.

Dr. Spitalnik suggested that, while thinking about what is important to people with ID and their families, the Committee should also consider services and support to a larger population as well as policies and their implications. Dr. White-Scott reminded the members that a new President/Administration may be the recipient of the 2016 RTP. Ms. Stacey Milbern asked if the Committee can make an educated guess on what might be included in the next President's disability agenda. Members expressed belief that it would be very difficult to guess. Mr. Habib asked if it was possible to meet in small groups first to generate the comprehensive list. Dr. Spitalnik responded that, since the Committee meets infrequently, it would be better to have all the discussions in a larger group first. Ms. Lisa Pugh agreed with this suggestion.

Ms. Pugh expressed belief that trends in Medicaid, and ways in which they are moving toward Managed Care, will cause change in community living arrangements. She continued by saying that another example is education and privatization of schools and how they will eventually impact public schools. Ms. Weintraub suggested the topic of safety and violence against people with ID. She talked about the Ethan Saylor's case in Fredrick, Maryland, and the unfortunate incident with law enforcement that led to his death. Ms. Julie Clark agreed and added that there are current initiatives in the law enforcement agencies that are aimed to research police officers' interactions with people with intellectual and developmental disabilities. Dr. Hawkins said that there are many civil rights groups and individuals involved in criminal justice system and people with ID should be also included and play a role in these conversations.

Ms. Margaret Schaefer, from the U.S. Department of Homeland Security (DHS), explained that interaction between law enforcement and individuals with disabilities is very important, and can make a good topic for the next Report. Ms. Swenson added that the school to prison pipeline can

also be a related piece to the criminal justice system. For example, compared to the general population, African-American boys' individualized education programs are four times as likely to be suspended and/or expelled. Commissioner Bishop stated that a 2012 Report by the National Disability Rights Network also focused on the juvenile justice system and the school to prison pipeline for various populations and can be served as a resource tool. Mr. Berns added that Arc of the United States has also worked in the area of criminal justice system in the last couple of years through the National Center for Criminal Justice and Disability. He believed that this might be a good topic to be explored by the Committee, since there are currently bipartisan reform efforts around it. Mr. Berns stated that although this topic is very important, he would also like to suggest the lack of portability of Medicaid from state to state as a potential topic. Ms. Williams responded that the 2012 PCPID Report was on Managed Long-Term Services and Support and to some degree captured some of these discussions. Ms. Swenson suggested framing of the Medicaid portability within a larger picture of Medicaid modernization, because the limitation of asset at the Social Security Administration is seen as a part of this ongoing problem.

Mr. Capone said that he believes the next Report should revolve around incentivizing employers to hire people with disabilities and abolish the 14(c). Section 14(c) of the Fair Labor Standards Act authorizes employers, after receiving a certificate from the Wage and Hour Division, to pay Subminimum wages - wages less than the Federal minimum wage - to workers who have disabilities for the work being performed. Mr. Zach Holler added that individuals with ID are often discouraged from joining the workforce, because they may lose their Medicaid waivers. So, there should be a Medicaid modernization and people should be encouraged to work and have employment opportunities available to them. Dr. Sheli Reynolds stated that the Committee should look at these issues not only through the lens of public sector, but also through the long-term support that can be expanded to cover federal as well as non-federal funding. She said "this is about figuring out the life span approach to services." Mr. Jim Brett suggested discussing a topic in which unveils ways to support states in training staff and providers to support integrated employment in general. Ms. Leola Brooks from the U.S. Social Security Administration added that financial literacy should also be included in the discussions.

Mr. Brandt expressed interest in pursuing the criminal justice in the field of intellectual and developmental disabilities as a potential topic and added that the issues with healthy relationships and promotion of healthy relationship and socialization, as well as social isolation are different dimensions of this topic. He shared with the Committee that self-determination and self-advocacy are also very important topics and should be considered.

Dr. Howard Caro-Lopez, with the U.S. Department of Transportation (DOT), stated that the topic of safety and violence is very broad and can be interpreted in many ways. He added that the questions around accessibility in transportation for people with disabilities can intersect with the questions of public safety as well. Dr. Caro-Lopez shared with members that DOT has begun making contributions in this area and would welcome the opportunity to integrate that into a future Reports of the Committee in the area of criminal justice. Mr. Dan Habib added that the segregation of people with ID in this area is a topic worthy of exploration.

Mr. Strautmanis suggested the following additional topics: 1) the incidents of wandering among individuals with autism; and 2) housing and accessible living for people with intellectual and developmental disabilities.

Dr. White-Scott explained that the level of sexual abuse that leads to some of the issues, and why people get caught up, in the criminal justice system is very high. She said that the level of sexual abuse prior to going into prison within the criminal justice system is heartbreaking and makes it very difficult for the individuals to deal with their overall life issues. Mr. Ricardo Thornton agreed and added that appropriate education for advocacy groups and police officers is an important factor. Dr. Spitalnik urged the Committee to think about the 2016 RTP through a larger political context, because the country is at the cusp of a new Administration, and as members we do not know who will receive, read, and act on the Report.

(Afternoon Recess)

AFTERNOON SESSION

Discussions of the Workgroups and their Private Sessions

Workgroup Members

Three (3) PCPID Workgroups were formed. The Workgroups started their private brainstorming sessions, immediately. The selected Workgroup Spokespersons reported the following information to the full Committee:

Workgroups Report Out, Full Committee Discussion and Selection of a Topic

Workgroup Spokesperson/Members

Workgroup #1: Dr. Deborah Spitalnik (Workgroup Spokesperson)

(Sue Swenson, Jim Brett, Stacey Milbern, Susan Axelrod, and Zach Holler)

Dr. Spitalnik reported that Workgroup #1 discussed the importance of criminal justice and the safety of people with disabilities as well as the violence against people with ID. Workgroup members, however, mainly focused on Medicaid, from the perspective of the transition to a new Administration and the importance of preserving of Medicaid, and the portability issues of Medicaid. The Workgroup also discussed issues of equity, Medicaid reform and home and community-based settings (HCBS), and how essential it is to all service systems that support people with ID in each state.

Dr. Spitalnik added that the Workgroup also raised the discrete issues of transition from school to adult life and supported decision-making as some of the other potential topics.

Workgroup #2: Liz Weintraub (Workgroup Spokesperson)

(Dan Habib, Peter Berns, Sheli Reynolds, and Gerrie Hawkins)

Ms. Weintraub explained that Workgroup #2 identified four different topics: 1) employment (how to engage employers in the public and private sector to hire people with disability); 2) post-secondary education opportunity; 3) training of professionals; and 4) replicating the School Wide

Integrated Framework (SWIFT), which is a model to scale up inclusive education, nationally, and to ensure that students with significant disabilities are fully included in the general education.

Ms. Weintraub also described that the Workgroup discussed the barriers of social isolation, due to poverty and lack of social support or victimization, etc. The members of Workgroup #2 believed that the topic of criminal justice and civil rights were very important to be explored in a report. The topic of “disability as diversity” came up within the group through the following points: employers often do not want to hire people with disability; required sophisticated knowledge about disability; required proactive approach; awareness of the “cliff” (this is a metaphor to explain that when people with disabilities become adults, they are likely to lose their services and support—what the bridge should look like is that instead of falling off that cliff, they get help to be landed to the other side of the bridge safely); ensuring that the voices of people with ID are included in the Report through success stories.

Workgroup #3: Lisa Pugh (Workgroup Spokesperson)

(Jack Brandt, Tinisha Agramonte, Leola Brooks, Sharon Lewis, Sheryl White-Scott, Margaret Schaefer, and Betty William)

Ms. Pugh explained that the Workgroup came up with four potential topics. The group started talking about data that is showing that most students with disabilities in school spend time in segregated environments and there have not been any past Reports on the least restrictive environments, alone. There is an urgent need for inclusive education and ending segregation in education and beyond. The Workgroup also explored the potential of the pipeline of segregation across the age span (when young children are spending time in segregated environments in the preschool ages, this will become a trend across their lifespan). The issue of guardianship in supported decision-making was also discussed within the Workgroup. The issue of aging of people with ID was considered as a very timely topic by the group. The Workgroup further discussed the criminal justice and the number of individuals with ID in the criminal justice system and the available data by the private as well as the government agencies around this.

Ms. Pugh reported that Workgroup members discussed the priority in terms of the timing for the Report, organization of the Report, timelines, and cross cutting pieces that are important to be included in the Report.

Other Relevant Discussions

Mr. Habib asked how intrinsic the topic of Medicaid reform is to all the point raised by the Workgroups in their discussions. Dr. Spitalnik responded that there is the issue of preserving Medicaid and changes in Medicaid and, basically, if this benefit was to disappear, more than 50% of any of the service dollars that come to developmental disabilities community would be in danger. Ms. Pugh and Dr. Reynolds talked about the number of people with ID who are not accessing the long-term services and support and thousands of people currently on waiting list for Medicaid-funded support in every state. Dr. Hawkins interjected that another issue is Medicaid fraud—how do people with disabilities help move the conversation from focusing on fraud to educating the community when it comes to Medicaid complexities. Mr. Berns added

that, according to the “State of States by Dr. David Braddock,” there are five million people with ID who are in waiting lists, and there are only 685,000 individuals who receive Medicaid-funded HCBS. There are only 460,000 family caregivers that receive any Medicaid-funded family support, and there is likely an overlap in those households. Ms. Axelrod expressed belief that these statistics include adults with ID, only. Ms. Swenson explained that the “HCBS waiver” is not designed to serve all people with ID; it was a waiver from institutional placement, so it was always organized around people with, what would rise to a federally-defined, developmental disabilities.

Ms. Swenson added that the State of Maryland conducted an analysis of its waiting list and found that the number of people on waiting list shrunk dramatically because: a) individuals did not know they were on the waiting lists because a social worker added their name without telling them; b) some individuals were still at a very young age; c) some individuals passed away; and d) some individual moved out of state.

Recapping the Discussions, and Expectations for the Next Day
PCPID Chair, DFO, and Members

Chairwoman Petty and Commissioner Bishop thanked the members for their excellent contributions to the first-day of the PCPID Meeting. They shared with the Committee Members that another round of full discussions about potential topics, as well as the rollout of PCPID 2015 RTP (with Dr. David O’Hara), will occur on the second-day of the meeting.

(Afternoon Recess)

DAY TWO

Call to Order

Julie Petty, PCPID Chair

The August 4, 2015 meeting was called to order by Chairwoman Petty who welcomed the Committee members to the second day of the meeting. She opened the floor to new ideas and discussions regarding the potential topics/themes for the PCPID 2016 RTP from the day before.

***Discussion of Prospective Focus Areas/Themes for the 2016
Report to the President, Formation of New Workgroups, and Future Meetings***
PCPID Chair, DFO, and Members

Commissioner Bishop explained that, yesterday, the Committee came up with the following five possible topics for the next Report: 1) Disability as a Civil Rights Issue and Dimension of Diversity; 2) Self-Determination and Supported Decision-Making (Self-Directed Life); 3) Criminal Justice; 4) Community Life across the life Span; and 5) Medicaid/Long Term Services and Support. Underneath these topics, there are multiple discussions on different

themes. Commissioner Bishop stated that the PCPID staff has developed a one-pager to reflect all the discussions from the first day of the meeting. He added that the one-pager is an internal document to the Committee and it does not include all the themes, but rather it includes the common themes discussed in all three PCPID Workgroups. He encouraged the members to review the one-pager and discuss the themes and add more themes to the document, as appropriate. Mr. Brandt said that he would like to see self-determination and civil rights of people with ID under Supported Decision-Making as a separate theme. Dr. Spitalnik added that under Medicaid, she would like to see an explanation that Medicaid is the foundation for services at the state-level; also HCBS should be added to the existing themes. Ms. Pugh and Mr. Habib stated that they would like to incorporate trends of segregation, earlier ages for students with ID, and pipeline of segregation into adult services.

PCPID staff took notes from the members' discussions of potential topics and themes. Members agreed to review the suggested topics at a later day and if necessary add to or delete from this list. The comprehensive list of suggested 2016 topics and subtopics follow:

Overall Constructs regardless of Topic

- Disability is a dimension of diversity and a civil rights issue
- People with I/DD from diverse backgrounds experience greater barriers (victimization, criminal justice, educational settings, employment)
- Self-determination (person with I/DD and all family members)
- Community living
- Decreased social isolation (education, employment, meaningful roles, etc.)
- Relevant to what people with I/DD want in their lives (representing their voice)
- How to think about people with I/DD (compelling, placed into context of lives lived everyday and urgent) with an immediate action step of something to do (roadmap of where to go)

Topic #1 Disability as a Civil Rights Issue and Dimension of Diversity

- Awareness of I/DD community among diversity agendas
- Reduce barriers of social isolation (due to poverty)
 - Breaking down attitudinal barriers
 - Training and tools to help increase awareness and understanding of differences
 - Inclusive and high-performing workplace culture

Topic #2 Self-Determination and Supported Decision-Making (Self-Directed Life)

- Rights of people with I/DD
- Supported decision-making and reforming guardianship
- Self-advocacy for persons with I/DD
- High expectations, awareness and education for parents, hospitals, etc. of supported decision-making

- Inclusive of aging population acquired disability (need to determine how is this related to I/DD?)
- Role and self-determination all family members

Topic #3 **Criminal Justice**

- Social Isolation
- Issues with healthy relationships
- Law enforcement
- Violence
- Emotional abuse and neglect
- Safety techniques (self-protection)
- Bullying and bullied
- Human trafficking
- Training of the prosecutors
- Victimization

Topic #4 **Community Life across the Life Span**

- Awareness of “Cliff” (when one becomes an adult)
- Stress and lack of social support
- Accessible transportation
- Community living/housing
- Healthy relationships
- Inclusive education as pathway to employment (birth to higher education)
- Segregation

Topic #5 **Long-Term Services and Support (LTSS)/ Medicaid**

- Medicaid (Foundation and Modernization/Reform)
 - Portability issues
 - Self-determination of person and families
 - Increasing buy-in to Medicaid and also follow along supports employment
 - Role of family caregivers and natural supports
 - Marriage penalty – marriage equality
 - Managed care
 - Self-directed services
 - HCBS settings rule
- Access to LTSS/Medicaid (and waiting lists)
- Family and aging caregivers
- Recognition by Health Resources and Services Administration (HRSA) as I/DD as special population within health to increase awareness within the medical community

Presentation on the Multimedia Production of the 2015 Report

David O'Hara, PhD

Dr. O'Hara started his session by thanking the Chair, DFO, and members for the opportunity to present to the full Committee. He congratulated the Committee on the completion of the 2015 Report and added that there should be universal access to technology (i.e., using smart and multimedia technologies) to improve the quality of lives of people with ID. Dr. O'Hara stated that his colleagues at the Westchester Institute of Human Development, AbleLink Technologies, and the RIX Center in the United Kingdom believe that multimedia can really be a critical tool for self-advocacy, self-determination, and real choice in how services are structured, designed and delivered to people with ID.

As examples, Dr. O'Hara displayed three video clips that illustrated how technology can influence the creation of infinite possibilities for people with ID and their families, and enable them to achieve a high quality life. The first video was created by a mother who uses smart technology devices to enable his son (an individual who lives with developmental disabilities) to experience self-determination and achieve a high quality life. She uses "Wiki" which is one of the foundational person-centered tools in allowing her to achieve this goal. Dr. O'Hara expressed belief that Wiki might be a relevant tool in enabling the PCPID 2015 Report to reach out to its widest possible audiences. He explained that making the Report available in multimedia resource around the goal of improving the lives of people with ID requires an incremental process. The first step may require taking the kinds of video clips that already exist to illustrate every one of the points identified in the Report as critical to ensuring that technologies are used to achieve quality of lives, and make available to people in a structured way as a collateral element to the existing Report. Dr. O'Hara explained that there should be links in the existing Report to this kind of multimedia material that would help people see exactly how the technology could play a role and the beauty of Wiki (showing the interaction, exchange, dialogue, and mutual support in educational, social, and health-related goals).

Q&A Session: Presenter-Committee Dialogue

PCPID Members

Ms. Brooks asked if Dr. O'Hara is suggesting that the Committee should focus on each area separately as a roll out strategy and as opposed to the entire Report. Dr. O'Hara responded that the Report can be disseminated the way it is drafted now, and then the members can add to it as time goes by. He added that one challenge will be finding the kinds of video or multimedia material that is out there and exemplifies the principles that the Committee would like to deliver by focusing on this technology. Mr. Habib asked if the Wiki platform could be primarily used to disseminate and advertise the Report. Dr. O'Hara responded, "Yes." Ms. Swenson explained that there might be two approaches to using technology—one is "let's change policy" and the other one is "technology is out there, so let's use it." Dr. O'Hara agreed and added that, indeed, there is a 45-minute self-directed training module that goes with the Wiki to teach families how to create their own Wiki (this training is currently offered in the United Kingdom and will be available in the United States soon).

Ms. Swenson suggested that the "Additional Resources" section of the Report be served as the multimedia platform for the document. Mr. Jack Brandt asked if members of the Committee can

work with the staff to create the PCPID Wiki. He shared with the members that he has developed a similar website through his full-time job. Ms. Weintraub asked if the concept could be explained again. Ms. Pugh responded that as the video shown by Dr. O'Hara illustrated, there are several spires that comes off the center (intuitive person-centered planning, in our case it will be PCPID Report) and would link to perhaps a video of a Committee member reading a script of certain recommendations and then there would be another tangent that would link to a video that is relevant to that areas of recommendations. Mr. Habib added that Facebook might not be a good option to replace the PCPID Wiki, because it is not organized in a way that would be self-sustaining. Mr. Habib asked the PCPID leadership if there will be monitory resources to support this initiative. Commissioner Bishop responded that it depends upon timing because as the Committee is planning to release the 2015 Report, it is also planning to develop the 2016 Report. He stated that although the agency cannot make any promises at this time, there will be a potential.

Mr. Brandt interjected that there are other platforms such as Facebook, WordPress, and Prezi (presentation software that uses motion, zoom, and spatial relationships to bring ideas to life) that could help figure out the best platform. Mr. Habib agreed and said that using Prezi can be a viable option and perhaps using YouTube channels and videos can be another feasible option. Chairwoman Petty stated that she would like to see a Wiki that includes the four areas of PCPID Report on technology, and a video on each area, to get the message out to developmental disabilities network (the committee's audience must be as broad as possible). Ms. Weintraub suggested that Chairwoman Petty make the *introductory* video.

Mr. Berns urged the Committee to set up some objectives and think about what is going to be manageable and accomplished, particularly given the resource constraints. He stated that the primary objective, for example, can be "to release simple version of information about the Report through existing social media and to get real stories from individuals with ID on how they use technology." This should also include an invitation to feeding information into the PCPID 2015 Report website and to identifying specific technologies that are being successfully used in supporting people with ID to live in the community.

(Afternoon Recess)

AFTERNOON SESSION

Further Discussions on Multimedia Production and Rollout Strategy PCPID Members

Chairwoman Petty resumed the meeting. She mentioned that members discussed the possibility of developing the PCPID Wiki during their lunch break. They believe that the Committee could create a Wiki, displaying different aspects of the Report and letting various audiences to have access to it. She stated that the first thing that the Committee would have to do is to make the Report material 508-complaint. Then, the Committee can use the general Wiki process and design for an optimal PCPID Wiki framework/infrastructure (with the help of Jack Brandt, Dan Habib, and PCPID staff). Ms. Petty asked the members to share any videos and personal stories

that are relevant to the contents of the Report with her and the PCPID staff. She stated that at the next meeting, there will be opportunity to videotaping different members (reading the key recommendations in each focus area of the Report).

Commissioner Bishop explained that with regards to the design of the actual Wiki, the Committee should keep in mind the initial message that this page attempts to communicate with its audiences. He added that one of the main points of the 2015 Report is to ensure that when technology is being developed individuals with ID are kept in mind and that technology apps are developed with recognition of, and specifically for, people with ID (referring to definition of cognitive accessibility and cognitive design that the Committee is recommending to the President).

Ms. Pugh stated that one main ideas in the Report is that technologies that people depend upon in their everyday lives need to be accessible for people with disabilities; including people with ID, and that the use of certain technologies can make life easier and facilitate independence for all people with intellectual and developmental disabilities. Ms. Brooks asked whether or not there would be an opportunity to produce the Report in other languages. Commissioner Bishop responded that PCPID has done this in the past and the Committee leadership will research and explore this option.

Summary of Deliberations, Proceedings, and Next Steps

Chair and DFO

Chairwoman Petty and Commissioner Bishop outlined the next steps as:

1. Finalizing the hard copy of the PCPID 2015 Report.
2. Setting-up technical assistance calls with the PCPID Workgroup Lead/*Ex officio* Representatives to re-edit certain recommendations.
3. Reviewing the “Introduction” section of the Report for plain language and accessibility (Dr. Spitalnik and Ms. Weintraub volunteered to assist with this task).
4. Creating initial Multimedia and 508-complaint platforms (Jack Brandt volunteered to take the lead). This item included the following steps:
 - Collecting personal stories, videos and other materials to be used in the “PCPID WIKI”
 - Using plain language, *SurveyMonkey* (Ms. Pugh volunteered to assist with this task) and PCPID generated short videos, etc.
5. Scheduling of the next PCPID In-Person Meeting in October or November 2015.

Meeting Adjournment

PCPID Chair

Chairwoman Petty adjourned the meeting.

ACTION ITEMS:

PCPID Members

1. Submit travel expenses to the PCPID Program Assistant for reimbursement purposes five business days after the meeting. (Completed)
2. Cast electronic voting ballots on the PCPID 2015 Report to the President after Friday, August 21, 2015. (Completed)

PCPID Work Group Leads and Ex officio Representatives

1. Participate in technical assistance calls with the PCPID Workgroup Lead/*Ex officio* Representatives by Friday, August 21, 2015. (Completed)
2. Share additional editorial comments on the 2015 Report to the President with the PCPID staff by Friday, August 21, 2015. (Completed)

PCPID Staff

1. Convert the meeting recording into minutes by Friday, October 2, 2015. (Completed)
2. Setup and participate in technical assistance calls with the PCPID Workgroup Lead/*Ex officio* Representatives by Friday, August 21, 2015. (Completed)
3. Finalizing the 2015 PCPID Report to the President. This included the following steps:
 - a) Collaborating with the Workgroup leads and the *Ex officio* representatives to address additional comments on the Report
 - b) Reviewing the “Introduction” section of the Report
 - c) Disseminating the updated Report among the members by Friday, August 21, 2015. (Action Item #3 - Completed)
4. Creating Multimedia and 508-complaint platforms (Jack Brandt volunteered to take the lead). This item included the following steps:
 - a) Collecting personal stories, videos and other materials to be used in the “PCPID WIKI”
 - b) Using plain language, *SurveyMonkey*, and PCPID generated short videos, etc.
 - c) Updating the Committee (Action Item# 4 - In Progress)
5. Scheduling of the next PCPID In-Person Meeting by Friday, August 21, 2015. (Completed)