



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

Committee Webinar/Conference Call
May 11, 2015
~Minutes~

Citizen Members

Julie Ann Petty, Chair
Peter Berns
Jack Martin Brandt
Jim Brett
Kenneth Capone
Micah Fialka-Feldman
Dan Habib
Stacey Milbern

Lisa M. Pugh
Susan Ramirez
Michelle "Sheli" Reynolds, PhD
Mike Strautmanis
Ricardo T. Thornton, Sr.
Elizabeth Weintraub
Sheryl White-Scott, MD
Betty Williams

Ex officio Members and Representatives

Mark Gross
Representing the Honorable Loretta Lynch
Secretary, U.S. Department of Justice

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

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

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

Charlene Wills
Representing the Honorable Julián Castro
Secretary, U.S. Department of Housing and
Urban Development

Yvette Rivera
Representing the Honorable Anthony Foxx
Secretary, U.S. Department of
Transportation

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

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

Leola Brooks
Representing the Honorable Carolyn Colvin
Commissioner, U.S. Social Security Administration

The Administration on Intellectual and Developmental Disabilities-PCPID Staff

Aaron Bishop, M.S.S.W.
The Administration on Intellectual and
Developmental Disabilities (AIDD)
Commissioner and PCPID Designated
Federal Official (DFO)

Loretta Hobbs, PhD
PCPID Consultant

Madjid “MJ” Karimi, PhD
PCPID Team Lead

Sheila Whittaker
PCPID Program Assistant

The PCPID Virtual Meeting Proceedings

Roll Call and Introduction of Dr. Loretta Hobbs

MJ Karimi, PhD, PCPID Team Lead

Dr. MJ Karimi started the May 11, 2015 virtual meeting of the President’s Committee for People with Intellectual Disabilities with taking a roll call, making housekeeping announcements, introducing the consultant to the Committee (Dr. Loretta Hobbs), and providing instructions for a successful webinar. He turned the meeting over to Commissioner Aaron Bishop to provide greetings and welcoming remarks to the participants.

Greetings and Presentation of PCPID Chair

Aaron Bishop
Commissioner, AIDD
Designated Federal Official, PCPID

Commissioner Aaron Bishop welcomed participants and thanked PCPID members for joining the meeting. He stated that since the last virtual meeting on April 7, 2015, the Committee has made significant progress in developing the Report to the President (RTP), focusing on the technology needs of people with Intellectual and Developmental Disabilities (IDD). Commissioner Bishop explained that the recommendations document based on the PCPID Workgroups discussions was prepared and sent out by Dr. Karimi. He identified one of the meeting’s goals as to provide a forum to Workgroup leaders to walk the Committee through the recommendations, and take questions from the members.

Commissioner Bishop congratulated six members (Mr. Berns, Mr. Brett, Mr. Capone, Mr. Holler, Dr. Spitalnik, and Ms. Weintraub) who were reappointed by the President to continue

serving PCPID as Citizen Members on May 8, 2015. He added that the PCPID staff will contact the re-appointees to assist them with the submissions of their required paperwork in the next couple of weeks. Commissioner Bishop, then, turned the meeting over to Chairwoman Julie Petty.

Opening Remarks, Call to Order, and Meeting Overview

Julie Petty, PCPID Chair

The PCPID Chair, Ms. Julie Petty, welcomed participants and called the meeting to order. She expressed belief that it is exciting to know that many meeting's participants are interested in the topic of technology and its impact in the lives of people with I/DD. Chairwoman Petty also congratulated the individuals who were reappointed to serve as the PCPID Citizen Members.

Ms. Petty also thanked the PCPID Workgroups for working around the clock to collect information on technology for people with Intellectual Disabilities (ID) in the following focus areas: Education, Community Living, Health and Wellness, and Economic Well-Being. She stated that the Committee would like to hear about each Workgroup's experience in developing the key recommendations for the Report.

Approval of Agenda and Minutes (April 7, 2015)

PCPID Chair

Chairwoman Petty requested a motion to approve minutes of April 7, 2015 Committee Meeting and the meeting agenda. Ms. Liz Weintraub made the motion to approve the minutes of April 7, 2015 Meeting and Mr. Ricardo Thornton seconded the motion. The Committee voted, unanimously, to accept the minutes as well as the meeting agenda.

Progress on the 2015 PCPID Report to the President

PCPID Chair

Chairwoman Petty thanked Ms. Lisa Pugh and Dr. Karimi for preparing a *SurveyMonkey* to gather Committee's input on the title of the Report. She asked Ms. Pugh and Dr. Karimi to present the results of the survey to the full Committee.

TITLE OF THE REPORT

Lisa Pugh, PCPID Member, and MJ Karimi, PCPID Team Lead

Ms. Lisa Pugh began her presentation by stating that the survey was shared with the members and encouraged them to come up with a consensus on the title of the Report. She added that the timeframe given to members to share their input was five business days, in which more than half of the Committee participated and responded. Ms. Pugh reported that the result was very much unanimous as the majority of participants agreed on the following title for the 2015 RTP:

*Leveling the Playing Field: Improving Technology Access and Design
for People with Intellectual Disabilities*

Ms. Pugh added that staff received several comments to mortify the title by removing the precursor of “Leveling the Playing Field.” She also reminded the Committee of the definition for technology determined by her Workgroup. The definition of *technology* for the purpose of this Report is as follows: “the use of advances in science to support people and society, to reduce barriers, and to make everyday world more accessible.”

Chairwoman Petty asked the members if they had any new comments on the title of the report. Ms. Liz Weintraub stated that she would like to see the precursor (Leveling the Playing Field) as a part of the Report title, because it will provide equal opportunity to people with disabilities to be included in the emerging technologies. Dr. Karimi added that PCPID staff solicited further input from all members to maintain and/or remove the first part of the title. He added that not many members favored the removal of the precursor, which resulted in adaptation of the entire title as it was initially proposed.

Chairwoman Petty, therefore, confirmed that the title would appear on the 2015 RTP as: “Leveling the Playing Field: Improving Technology Access and Design for People with Intellectual Disabilities.” She then asked the Education Workgroup Lead, Mr. Dan Habib, to start his updates (for 5 minutes) and Q/A session (for 15 minutes).

EDUCATION WORKGROUP UPDATES AND Q/A SESSION

Dan Habib, PCPID Member and Workgroup Lead

Mr. Habib thanked the members of his Workgroup (Ms. Glinda Hill, Mr. Zach Holler, Mr. Ricardo Thornton, Ms. Liz Weintraub, & Dr. MJ Karimi) for all their hard work on developing the proposed recommendations. He added that the Workgroup decided to divide the topic of “Education” into the following five areas:

1. Education and Assessment Materials
2. Higher Education Access
3. Online Learning
4. Research and Development
5. Family and Student Engagement

Mr. Habib reported on the key recommendations, on the aforementioned areas, and provided the following clear examples:

Increase Production and Availability of Cognitively Accessible Educational Materials

Motivation for recommendations:

There is a lack of production and dissemination of educational and assessment materials that are designed from the start to be cognitively accessible.

Examples from Key Recommendations:

- The Elementary and Secondary Education Act (ESEA), Individuals with Disabilities Education Act (IDEA), Higher Education Opportunity Act (HEOA)

and other federal legislation must embed the use of technologies and cognitively accessible curricula and assessments that enable students with ID to access the general education curriculum and to participate in the activities and instructional environment of general education classrooms

- The U.S. Department of Education should issue a “dear colleagues” letter that makes a strong recommendation that all educational curriculum being purchased by schools (K-higher education) meet current industry standards for cognitive accessibility (such as EPub3: the latest version of the EPub format, a widely used and easily accessible format for representing digital publications)
- Include ID as a beneficiary group in § 121 U.S. Copyright Law, which requires limitations on exclusive rights: reproduction of materials for people with disabilities (i.e. the Chafee Amendment).

Increase Access to Higher Education for Students with ID

Motivation for recommendations:

- Lack of cognitive (and other) accessibility designed in higher education curriculum (both online and brick-and-mortar courses)
- Uncertainty about the technological (and other) supports that students with ID are legally entitled to (under the Americans with Disabilities Act or ADA, 508, 504, etc.) within higher education
- Lack of K-12 focus on advanced career choices for students with ID.

Example from Key Recommendations:

The Office of Special Education and Rehabilitative Services, the Office of Civil Rights and the Office of Post-Secondary Education should issue a clarification on the rights of individuals with ID to post-secondary settings under the civil rights legislation for higher education. This would include guidance on the question: “To what extent can an accommodation (including, but not limited to, technological supports) be required if an individual wants to engage in a course of study?”

Increase Access to Online Learning for Students with ID

Motivation for recommendations:

Lack of cognitive (and other) accessibility designed into online and blended courses.

Example from Key Recommendations:

ESEA, IDEA and HEOA and other federal legislation must include cognitive design principles in order to address access to online learning. These principles would include online supports (vocabulary and thematic supports, etc.) to enhance meaning and understanding for content at varying levels of

reading difficulty. Intermediate steps might include the funding of research on cognitive design principles, personalization and digital learning; the funding of prototypes of flexible and responsive online learning systems designed to support usability; descriptive research of promising practices in online learning for students with ID.

Ms. Weintraub asked what types of incentives the Workgroup suggested to for-profit organizations in developing the cognitively accessible materials for students with ID. Mr. Habib responded that one approach that was discussed, within the Workgroup, was to provide companies with the tax incentives when cognitively accessible materials for the students with ID were produced. Mr. Mark Gross asked how should the Workgroup define what is the standard in accessibility, and what is required under the ADA, 508, 504, etc. versus what is desired under these laws? Mr. Habib responded that it would be important to define what the Committee means by cognitive accessibility in the Report. He said that members of the Workgroup believed that when taking college-level classes people with ID should know what their rights are and regrettably research shows this is not the case when it comes to accessible materials.

Ms. Yvette Rivera suggested defining the multi-use of accessible technologies that not only helps people with disabilities, but also benefits all users regardless of their abilities. Ms. Pugh agreed with the concepts of defining what the Committee means by “cognitive accessibility” and suggested that the Committee be very clear on conveying the message that people with I/DD have the ability to achieve the proficiencies at the same level of their peers (high educational expectations for people with I/DD). Mr. Ricardo Thornton asked if the topic of transition for people with ID was also discussed. Mr. Habib responded that the Workgroup lightly discussed the educational transition for people with I/DD from K-12. Dr. Karimi added that the general topic of transition to adulthood was fully discussed within the Economic Well-Being Workgroup.

Ms. Weintraub suggested that PCPID staff clearly address the differences between cognitive disabilities and ID in the introduction of the Report.

ECONOMIC WELL-BEING WORKGROUP UPDATES AND Q/A SESSION

Jack Martin Brandt, PCPID Member and Workgroup Lead

Mr. Brandt thanked the members of his Workgroup (Mr. Peter Berns, Ms. Leola Brooks, Ms. Julie Clark, Ms. Julie Petty, Ms. Yvette Rivera, & Dr. MJ Karimi) for all their efforts during the past month in developing the following key recommendations:

Overarching Recommendation

Technology must be accessible, affordable, and widely available to individuals with ID who can benefit from it at home, in their communities, and at work.

Recommendations on Employment

Department of Labor (DOL) should:

- Issue Technical guidance to the state/local Workforce Development Boards and the American Job Centers on programmatic accessibility and accessible technology as they

specifically relate to serving to one-stop customers with ID (DOL-Employment and Training Administration)

- Issue Technical guidance to the regions that include best practices and resources that can be used by federal contractors regarding the use of accessible technologies in the hiring and employment of individuals with ID (DOL-Office of Federal Contract Compliance Programs)
- Strengthen its efforts to increase employment of individuals with ID through the development, promotion and use of accessible technologies. This effort will include the review and addition of technology resources specific to individuals with ID offered through Office of Disability Employment Policy's Partnership on Employment and Accessible Technology, Job Accommodation Network, Disability.gov, the LEAD Center, and the Employer Assistance and Resource Center.

Recommendations on Economic Well-Being

U.S. Department of Education should issue guidance to:

- Highlight that the term "assistive technology" does include mainstream information and communications technology (e.g., technologies that are universally designed and mobile technologies that can utilize apps facilitating the employment of people with ID)
- Provide additional information and resources to the state vocational rehabilitation programs on the use of technology and related technology services as part of Individualized Employment Plans (IEPs).

U.S. Department of Health and Human Services should:

- Fund research that specifically focus on the use of technology to increase competitive, integrated employment outcomes for youth and adults with ID (i.e., the National Institute on Disability, Independent Living, and Rehabilitation Research)
- Conduct research and issue new guidance to enable coverage of universally designed mobile and mainstream technologies that provide the same functional assistance as currently covered items (i.e., the Center for Medicare & Medicaid Services).

Mr. Mike Strautmanis commended the Workgroup for their focus on increasing access to broadband technology since without access to high-speed Internet most of the technologies are unusable. Ms. Pugh suggested including a potential recommendation to encourage the Department of Education to issue additional guidance on the use of, and access to technology, for supplementary aid/services for transitional services for youth. Mr. Brandt responded that the Workgroup will certainly consider this as a potential recommendation. Ms. Weintraub requested that this recommendation be added in both Education and Economic Well-Being sections. Chairwoman Petty responded that this recommendation is more appropriate to be included in the Economic Well-Being section. Ms. Pugh and Ms. Rivera stated that they will provide PCPID staff with information on the potential recommendation regarding supplementary aid for transitional services for youth with ID.

COMMUNITY LIVING WORKGROUP UPDATES AND Q/A SESSION

Charlene Wills, PCPID Ex officio Representative Member and Workgroup Co-Lead

Ms. Charlene Wills started her presentation by thanking the Community Living Workgroup members (Ms. Susan Axelrod, Mr. Gary Blumenthal, Ms. Yvette Rivera, Mr. Ricardo Thornton, Ms. Liz Weintraub, & Mr. Ken Capone). She also thanked her colleagues at the Department of Housing and Urban Development or HUD (Ms. Michelle Aronowitz and others) for their assistance with her remarks. Ms. Wills stated that the Community Living recommendations were separated into the following three distinct groups:

1. Assistance
2. Discrimination
3. Housing Location Application

Assistance

- The Centers for Medicare & Medicaid Services (CMS)-Home and Community Based Services (HCBS) final rule should be expanded to include the use of technology as criteria for evaluating whether a program is successful in enabling the individual to be part of the community
- There should be an increase in technological applications for individual with I/DD for everyday living situations.

Example: The U.S. Department of Housing and Urban Development created a new housing counseling mobile app that allows smartphone and tablet users to locate housing counselors in their own area. Additionally, pre-purchase counseling can help individuals determine if they are ready for homeownership, and connect them with safer and more affordable mortgages. This app allows users to search for counseling agencies based on location and available languages. The app is also freely available to users and provides efficient and reliable information.

Discrimination

In 2013, HUD unveiled the first housing discrimination mobile app for iPhone and iPad. Developed by HUD's Office of Fair Housing and Equal Opportunity and Hewlett Packard, the app uses the latest technology to provide the public with a quick and easy way to learn about their housing rights and to file housing discrimination complaints, and inform the housing industry about its responsibilities under the Fair Housing Act. This app has been an important tool to assist fair housing groups and other civil rights advocacy organizations in their efforts to help individuals pursue their housing rights and industry to educate their members on their responsibilities. In addition to facilitating real-time delivery of housing discrimination complaints to HUD, the app can be used by individuals researching their housing rights after a natural disaster, when power outages make the iPhone/iPad one of the few ways to access the Internet. The app also provides information about the fair housing complaint process, and allows the public to

access HUD's toll-free discrimination hotline and link to the agency's fair housing website: www.hud.gov/fairhousing

Housing Location Application

Further technological applications such as the aforementioned app should be researched and funded to provide individuals with I/DD more seamless options for independent living, including the ability to ensure that all appliances are turned off after leaving home, monitoring the thermostat from an application and delivery of notices from landlords.

One of the public participants who identified herself as Wendy from California asked about the housing location apps and their current accessibility features for all end-users. Ms. Wills responded that this particular housing app is about to be launched and the Workgroup recommendation is to expand the app to include accessibility features that are accurate and easily identifiable.

HEALTH AND WELLNESS WORKGROUP UPDATES AND Q/A SESSION

Sheryl White-Scott, MD, PCPID Member and Workgroup Co-Lead

D. Sheryl White-Scott began her remarks by thanking the Health and Wellness Workgroup members (Ms. Susan Axelrod, Dr. Deborah Spitalnik, & Ms. Betty Williams) and Drs. Reynolds and Karimi for their assistance with developing the recommendations in the area of health and wellness. She added that the group started its work from the premise that "Health and Wellness" is very general, and looked at ways to coordinate with technology to benefit the wellness of people with I/DD. She added that some obstacles and barriers with the health and wellness of this population stay the same such as lack of training of support professionals, and lack of design and access. The Workgroup, therefore, was motivated to take a look at the landscape of the healthcare and learned that the Affordable Care Act (ACA) is by far one of the most influential pieces of legislation in the healthcare as well as the recent history of the United States. Dr. White-Scott explained that the Workgroup wanted to ensure that people with I/DD will have access to a full range of benefits that all citizens have through the ACA. The Workgroup, thus, used the ACA as an umbrella for its recommendations:

The Workgroup also wanted to ensure that technology supports individuals with I/DD in accessing and receiving appropriate quality health care, and enables health care systems to provide coordinated community-based health care and long-term care services as described in the ACA.

When looking at the ACA, the Workgroup identified the CMS as a major partner of the federal policy recommendations in this area.

The Workgroup divided its recommendations in the following three categories:

1. Individuals with I/DD
2. Training of Healthcare Personnel

3. Data, Information, and Technology to Shape/Formulate the Policies, Practices, and Future of Healthcare

Key Recommendations

- CMS' review and approval of Medicaid State Plan Amendments and Waivers includes the requirement the states fund appropriate personal and normative technology including iPads and other devices that facilitate the participation of people with I/DD in their own health care and health maintenance and wellness
- Technology support should be used for ongoing training of health care professionals to increase their skills, knowledge and understanding of people with I/DD (this should be implemented across the board)
- Promote the sharing of electronic records between health care systems and long-term services to improve care for individuals and provide longitudinal data for systems planning, including budgetary allocation.

Mr. Strautmanis suggested that while writing the Report, the Committee should try to emphasize community inclusion and coordination (e.g., people living in poverty, parents, students, educators, etc.) and to act as a catalyst to get this information out to the ground and into the community. Chairwoman Petty responded that each section of the Report will list different organizations and innovations, intending to connect people to these resources. Mr. Habib suggested that as PCPID is developing a report that is universally designed (i.e., embedding images, texts, videos, etc.), the Committee should gather and include real life examples in the Report.

For the record keeping purposes, Dr. Karimi shared a note from the Department of Labor regarding Ms. Pugh's earlier transition-related recommendation. The note stated that transition is a Department of Education issue and is covered under the IDEA funding and should be included under the "Education" recommendations. Ms. Hill confirmed that this section already includes this information.

PROCESS AND TIMING

PCPID Chair, AIDD Commissioner, & PCPID Team Lead and Consultant

Dr. Karimi provided a timetable and also stated that the PCPID staff will gather more recommendations to be incorporated in the 2015RTP. He added that the first draft of the Report will be shared with the Committee in the first week of June. Commissioner Bishop encouraged the PCPID Workgroups to continue their work and finalize and share their recommendations with the staff by the end of May. He also said that the PCPID leadership will meet to determine the dates for the next face-to-face meeting in which the final Report will be discussed in depth and be voted for.

Commissioner Bishop shared with the members that PCPID staff, and Mr. Habib, is currently working on the E-format and release of the Report after it goes on the vetting process through the Ex officio agencies. Ms. Weintraub suggested developing a short video to market the Report once it is finalized.

Next Steps and Agenda Items for the Next PCPID Meeting

PCPID Chair

AIDD Commissioner

Chairwoman Petty re-congratulated the six PCPID members for their reappointments to the Committee. She also thanked Ms. Susana Ramirez for her wisdom and for serving the Committee for a number of years. Ms. Ramirez appreciated the opportunity to be part of the Committee and encouraged the members to continue working hard and to contributing to the field of I/DD.

Dr. Karimi announced that PCPID staff will reach out to the re-appointees to schedule their swearing-in ceremony as well as annual ethics training. Commissioner Bishop shared with the re-appointees that today (5/11/15) is their last official workday until the onboarding process is finalized.

Meeting Adjournment

PCPID Chair

Chairwoman Petty made the motion to adjourn the meeting. Ms. Pugh made the motion to adjourn the meeting and Ms. Williams seconded the motion. The meeting was adjourned.

ACTION ITEMS:

PCPID Members

1. The PCPID Workgroups complete and submit their final recommendations to staff for inclusion in the PCPID 2015 Report to the President by **Friday, May 29, 2015**.
(Completed)
2. Ms. Lisa Pugh and Ms. Yvette Rivera provide PCPID staff with information on the potential recommendation regarding supplementary aid for transitional services for youth with I/DD by **Friday, May 29, 2015**. (Completed)
3. PCPID new re-appointees be ready to meet and complete their remote swearing-in ceremony and their annual ethics training by **Monday June 15, 2015**. (In progress)

PCPID Staff

1. Convert the meeting recording into minutes by **Friday, May, 2015**. (Completed)
2. Receive and incorporate the final recommendations, from PCPID Workgroups, to the Report by **Friday, May, 2015**. (Completed)
3. Complete and share the first draft of the PCPID 2015 Report to the President by **Monday, June 1, 2015**. (In Progress)
4. Schedule the swearing-in ceremony and ethics training for the PCPID re-appointees by **Monday June 15, 2015**. (In progress)