



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

Committee Meeting
November 9-10, 2015
~Draft Minutes~

Citizen Members

Julie Petty, Chair
Susan Axelrod
Jack Martin Brandt
Kenneth Capone
Micah Fialka-Feldman
Dan Habib
Zachary Holler
Stacey Milbern (via telephone)
Lisa M. Pugh

Michelle "Sheli" Reynolds, PhD (via
telephone on Day 2)
Deborah Spitalnik, PhD
Mike Strautmanis
Ricardo T. Thornton, Sr.
Elizabeth Weintraub
Sheryl White-Scott, MD
Betty Williams

Ex officio Members and Representatives

Regina "Gina" Kline, Esq. for Mark Gross
Representing the Honorable Loretta Lynch
Attorney General, U.S. Department of
Justice

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

Richard Davis and Speed Davis 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

Jeanine M. Lafratta for Michelle Aronowitz
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

Corinne Weidenthal for 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
Representing the Honorable Carolyn Colvin
Commissioner, U.S. Social Security
Administration

Gary Blumenthal (via telephone)
Representing the Honorable Jeff Rosen
Chair, National Council on Disability

Special Guests and Presenters

Julia Bascom
Deputy Executive Director
Autistic Self Advocacy Network
Washington, DC

Erik Carter, PhD, FAIDD
Associate Professor, Department of
Special Education
Vanderbilt Peabody College
Nashville, TN

Curtis L. Decker, JD
Executive Director
National Disability Rights Network
Washington, DC

Robert Dinerstein, JD
Professor of Law
Associate Dean for Experiential Education
American University, Washington College
of Law
Washington, DC

Tawara Goode, MA
Director, National Center for Cultural
Competence
Georgetown University Center for Child
and Human Development
Washington, DC

Ryan King and Susie King
Washington, DC

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

Morgan Whitlatch, JD
Senior Attorney
Quality Trust for Individuals with
Disabilities
Washington, DC

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

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

Ophelia McLain, DHA
Director, AIDD Office of Innovation

Madjid “MJ” Karimi, PhD, CPH
PCPID Team Lead

Sheila Whittaker
PCPID Program Assistant

Meeting Proceedings

DAY ONE (November 9, 2015)

Greetings and Introduction of PCPID Chair

Aaron Bishop, Commissioner
Administration on Disabilities
Designated Federal Official (DFO)
President’s Committee for People with Intellectual Disabilities

On behalf of the U.S. Department of Health and Human Services, Commissioner Aaron Bishop welcomed participants and thanked PCPID members for joining the fall edition of the PCPID Meeting. He congratulated the Committee Members for preparing and releasing a fascinating, well-received, and well-respected technology report in October. Commissioner Bishop stated the Federal Communications Commission (FCC) recently discussed and wrote a blog about the Committee’s 2015 Report to the President (RTP). He, then, turned the meeting over to the PCPID Chairwoman, Ms. Julie Petty.

Opening Remarks, Call to Order, and Introduction of Special Guests

Julie Ann Petty
Chair

The PCPID Chairwoman, Ms. Julie Petty, welcomed participants and called the meeting to order. She thanked the members and staff for their teamwork in completing the PCPID 2015 RTP. Chairwoman Petty added that during this meeting, members are expected to talk about the future marketing (known as PCPID Wiki) of the report, receive a number of presentations, and have discussion regarding the potential topic(s) for the Committee’s 2016 RTP.

Approval of Agenda and Minutes (August 3-4, 2015)

PCPID Chair and Members

Chairwoman Petty made the main motion to approve the minutes of the PCPID August 3-4, 2015 meeting. Ms. Liz Weintraub and Ms. Susan Axelrod seconded the motion to approve the minutes of the PCPID August 3-4, 2015 meeting. Chairwoman Petty also made a motion to approve the meeting agenda, which was seconded by Ms. Lisa Pugh and Ms. Betty Williams. The Committee voted to accept the minutes as well as the meeting agenda. Motion carried.

Self-Introductions (Citizen Members and Ex officio Representatives)

Citizen Members and *Ex officio* Representatives

Chairwoman Petty requested all members to introduce themselves and identify their affiliations with the Committee. This was done in a “round robin” format.

Updates on the PCPID 2015 Report to the President

Coleman Institute for Cognitive Disabilities—October 2015 Conference

Julie Petty, Aaron Bishop, and MJ Karimi

Chairwoman Petty stated that PCPID was invited to present the Committee's 2015 RTP at the 15th Annual Coleman Institute Conference on Cognitive Disabilities and Technology in Colorado on October 15, 2015. During this event, Chairwoman Petty, Commissioner Bishop, and Dr. Karimi provided a comprehensive overview of the report and its recommendations to more than 700 conference participants.

Commissioner Bishop added that a few representatives from the technology-related industries showed interest on the technical aspects of the report such as coding and the specific recommendation for developing an open repository, containing accessible information and resources for people with cognitive disabilities.

National Council on Disability (NCD) Quarterly Meeting

Dan Habib

PCPID Citizen Member

Mr. Dan Habib shared with the members that summarizing the entire 2015 RTP in a 20-minute presentation at the quarterly meeting of the NCD was a challenging task. During his NCD presentation, he first talked about the critical role of technology in being a big part of everyday life and reminded the audiences about the role of technology in communications, education, and employment. Mr. Habib stated that the title of the report (*Leveling the Playing Field: Improving Technology Access and Design for People with Intellectual Disabilities*) served as an entry point for the participants to understand the themes of the report, and was very well-received at this meeting. He also stated that a local newspaper in New Hampshire published a story about the PCPID 2015 RTP and used the same title as the "actual title of the article."

Mr. Habib reported that he also spoke about the technology interfaces in people's lives that one may take as a "granted," and how technology has been an intrinsic part of today's world. He added that when talking about the cognitively accessible design (the term that was used in 2015 PCPID RTP), he exemplified and compared two airline websites. One website was intuitive, used simple prints and imageries for accessibility and the other website was not very user-friendly. Mr. Habib expressed belief that the technological innovations in schools would not only provide all students with accessible materials, but also it will help teachers to properly accomplish their jobs (e.g., develop appropriate curriculums) at the first place.

Mr. Gary Blumenthal added that the PCPID RTP along with another report from NCD did an excellent job in explaining the role of technology, providing federal policy recommendations, and introducing several new definitions to the field of technology. Dr. Sheli Reynolds said that as the Director of Community of Practice for Supporting Families, she partnered up with the National Association of State Directors of Developmental Disabilities Services (NASDDDS) to highlight the Report in a national webinar, a few weeks ago. Dr. Reynolds expressed belief that the recommendations on long-term services and support (LTSS) were well-received by the state agencies during this national webinar.

Dr. Deborah Spitalnik encouraged the Committee members to think about the impact of the Report and how it should be further disseminated and shared with various audiences. Commissioner Bishop responded that some of the impact of the report can be tracked down by the web content system at the Administration for Community Living (ACL). For example, the number of times that the report was reviewed by the public could be easily determined. He also added that a few weeks ago the University of Kansas and the University of Maine held a mutual meeting to discuss the role of technology in the lives of older Americans. These universities were presented with information on the PCPID 2015 RTP, which helped them to have discussions and reach fruitful conclusions. Commissioner Bishop concluded that with the Assistive Technology Act program being recently transferred to the ACL, there will be many ways to disseminate and share this report with a broader audience.

Mr. Habib suggested setting up “Google Alerts” for precisely tracking down the impact of the report and getting good results in many other possible ways.

Discussions and Presentation of the PCPID Wiki

Further Instructions on Recording of the Videos

David O’Hara, Jack Brandt, Dan Habib, and MJ Karimi

Guiding Questions:

- *What specific concepts and highlights from the 2015 Report to the President should be included in the PCPID Wiki?*
- *What are some of the key recommendations in the report that should be included in the Wiki?*
- *What videos, additional resources, and websites should be added to the Wiki?*

Dr. David O’Hara, Chief Executive Officer of the Westchester Institute for Human Development (NY) began his presentation by stating that technology could be a part of the transformation for people with intellectual and developmental disabilities (I/DD). In terms of creating a good impact for the Report, he suggested that as many PCPID members develop video links that articulate why the 2015 PCPID RTP is important and what it has been designed to do. Dr. O’Hara, then, displayed an example to show the members the way that a Wiki model was developed to gather and disseminate information at the European Special Olympics games in 2014.

Dr. O’Hara also unveiled the preliminary format of the “PCPID Wiki” in which four focus areas (Education, Community Living, Employment, and Health and Wellness) of the report were highlighted and ready to adopt their own individualized videos and other resources.

Mr. Habib added that one important factor is how to represent the report in a more accessible and universally designed way. Wiki is a platform for dissemination of information in an accessible way, itself. He stated that in the last couple of months, PCPID staff worked with the members to prepare the accessible scripts for the videos relating to each focus area of the report.

Chairwoman Petty asked if the videos and the PCPID Wiki could be accessed through the [PCPID Website](#). Dr. O’Hara responded that the link can be added to this Website with the help of staff. Mr. Habib expressed belief that the PCPID Wiki should not be a static site; rather it

should be interactive and continue to grow overtime. He encouraged the members to discuss the guiding questions (see bullets points on the previous page). Mr. Habib suggested that each PCPID Workgroup should find a mechanism to review the scripts for accuracy and improvement. Mr. Jack Brandt suggested that the definition of *cognitive accessible design* be highlighted in an easy-to-understand format in the scripts and eventually on the videos.

Ms. Liz Weintraub asked, how could a visually-impaired individual might be able to use Wiki without any support system? Dr. O'Hara responded that when dealing with technology, someone might always need some level of supports. However, the PCPID Wiki will be designed to be self-directed. Mr. Habib added that the PCPID Wiki will also be in compliant with the most accessible standards (e.g., screen readers, image identification, close captioning, etc.). Commissioner Bishop stated that the federal government is required, by law, to release reports and other materials in a plain language and accessible format. This will be accomplished.

Chairwoman Petty suggested that the self-advocate members of the Committee be featured in the videos. She shared with the members that the recording of the videos will be rescheduled for a later date to give the workgroups more time to review the scripts and find answers to the guiding questions. She added that the timeline to complete the scripts is set for December 1, 2015. Mr. Habib suggested that at least two individuals from each workgroup volunteer to review the scripts before December 1st.

The following individuals volunteered to assist with reviewing the script and find answer to the guiding questions relevant to the PCPID wiki:

- **Definition of Technology and Introduction Section:** Lisa Pugh and Dan Habib
- **Education Section:** Dan Habib and Liz Weintraub
- **Community Living Section:** Ken Capone and Yvette Rivera
- **Employment Section:** Jack Brandt and Leola Brooks
- **Health and Wellness:** Dr. Sheryl White-Scott and Betty Williams (Dr. Deborah Spitalnik to review)

Dr. Spitalnik also suggested correcting the labeling of each section on the PCPID Wiki webpage; for example, instead of “learning”, the video can be labeled as “education.” Ms. Weintraub suggested that a group picture of the PCPID members be added to the PCPID Wiki (on “*About PCPID Section*” of the Wiki).

Mr. Habib summarized the above-mentioned information into the following points:

- Two volunteers from each workgroup were determined to review the scripts,
- Review of the scripts, examples, and resources should be completed by December 1st,
- The Committee’s leadership will decided on who will be reading the scripts in front of the camera,
- Members will provide feedback to the staff on what other resources should be used in the PCPID Wiki.

Dr. O'Hara expressed belief that this is a good strategy and suggested adding a link to the Wiki to enable the Committee to receive feedback from the users. Ms. Susan Axelrod encouraged the members to think about strategies to address each feedback, properly. Mr. Michael Strautmanis

agreed and added that the PCPID Wiki should be used as another empowerment tool for people to make them feel that they are part of this project. Dr. White-Scott asked how will the Committee do this on an ongoing basis and continue to grow and expand. Commissioner Bishop responded that the PCPID Wiki will be designed to filter out and take into account each feedback separately; a similar effort has been already started at the ACL-level. Mr. Strautmanis added that when responding to the feedback, it is important to keep the role of the Committee in mind and “be upfront.” Dr. Spitalnik said that there should also be clarity about the kind of input/feedback that the Committee “is asking for from the general public.”

Chairwoman Petty encouraged the members to put some thoughts into the “guiding questions” and share their future suggestions, via e-mail, with the staff.

PRESENTATION OF THE 2016 REPORT TO THE PRESIDENT

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

Civil Rights Issue

Curtis L. Decker, JD

Executive Director

National Disability Rights Network

Ms. Lisa Pugh welcomed and introduced the first guest speaker, Mr. Curtis Decker.

Mr. Decker started his presentation by taking the Committee through a history of civil rights movement in 1950’s and 1960’s for persons of color. He added that at that time the country needed a change in public perception about the rights of these individuals to live in the community and receive all the benefits of American life. The disability movement in 1970’s picked these themes for the basis of starting a “special education” trajectory. In recent years, the country has moved forward with the Ticket to Work and the Affordable Care Act programs to advocate for jobs and provide health insurance for people with disabilities. Mr. Decker stated that we, as a community, celebrate all of these successes but we still have a series of issues being secluded and restrained as students are not experiencing smooth transition to adult life. We, thus, need to ensure that the promise of community integration (as affirmed by the Olmstead Decision) is real. One other area that needs improvement under the Americans with Disabilities Act (ADA) is employment of people with disabilities. This is an area that is directly linked to housing and transportation services, which need to be reinforced in our present society.

Commissioner Bishop added that not only some students are secluded or restrained, but also they are suspended and expelled on a track to juvenile and criminal justice experience. Mr. Decker agreed and added that perhaps the community made a mistake in creating special education or special needs concepts; parents want to see their kids experience equality in education and not special education. Chairwoman Petty stated that when schools have a poor performance in education and transition services, students with disabilities get expelled and pushed through a pipeline into the juvenile justice system for behavioral problems. Mr. Decker agreed and stated

that we have to get the “civil rights community” to understand that there is a real problem in the juvenile justice system and that the right to equal education is only one way to prepare students with disabilities into entering their communities.

Mr. Decker expressed belief that “supported decision-making” is an important civil rights concept to enable people with disabilities to move away from the whole issue of guardianship and giving them the ability to be in control of their own lives.

Diversity

Tawara Goode, MA

Director, National Center for Cultural Competence
Georgetown University Center for Child and Human Development

Dr. Deborah Spitalnik welcomed and introduced Professor Tawara Goode to the Committee.

Professor Goode began her presentation by defining culture in its multiple dimensions, and cultural diversity which is different from diversity, itself. She also talked about the concept of multiple cultural diversities, the impact of the cultural diversity in the United States, including its territories and tribal communities, and cultural implications with self-determination, supported decision-making, and segregation in education.

Professor Goode defined culture as the “learned and shared knowledge that specific groups use to generate their behaviors and interpret their experience of the world.” She explained that culture can not only be learned, but it can be unlearned and is not limited to race and ethnicity. She stated that many within the disability community have been stuck solely on disability and not the person’s life beyond his/her disability that intersect with the person’s cultural identities. Cultural identities are used to describe differences in individuals. Professor Goode also described that by 2045, the nation will become “majority-minority” and discussed the impact of languages spoken in the United States on diversity. She further explained that people with intellectual disabilities (ID) are impacted by health disparities and discrimination. When looking at data, there are additional disparities that are based on ethnicity, language spoken, geographical location, and gender.

Q&A Session: Presenters-Committee Dialogue

PCPID Members and Guest Speakers

Ms. Pugh asked the presenters about some policy areas that the Committee should take into consideration when preparing the 2016 RTP. Mr. Decker responded that one area would be voting process for people with I/DD and another area is the topic of full-time employment and increasing the minimum wage as well as creating high expectations. Ms. Weintraub asked about the effective ways in which discrimination and prejudice could be eliminated. Mr. Decker responded that as a community, we have to be vigilant, develop protection processes and have the right to appeal and raise good questions. Mr. Strautmanis stated that the storytelling (whether through popular culture or films) can play a major role in fixing unconscious bias and stereotyping.

Mr. Habib asked about certain policies that effect and/or resonate with people with I/DD, especially those from minority groups such as lesbian, gay, bisexual, and transgender (LGBT) community. Professor Goode responded that there are some policy areas that are more actionable and imminent such as policies on health disparities in the intersection of race and disability, special education, and prison pipeline. Mr. Richard Davis asked how the community can create opportunities and tear down all barriers to change society's mind about what people are really capable of doing, regardless of their race, ethnicity, and disability status. Professor Goode replied that one essential framework for considering culture is that it can be unlearned. Ms. Yvette Rivera asked what should be the top priority for federal government, civil rights divisions, and what should government do differently in this area. Mr. Decker responded that with the current Administration, there has been a proactive approach towards issuing policies and regulations; however, the policy and underlying enforcement have to go hand-in-hand. Ms. Betty Williams asked how the enforcement would be possible when it comes to discrimination based on disability. Mr. Decker responded that one way is self-advocacy training to teach individuals that they not only have the rights, but also show them a mechanism to enforce those rights. Mr. Ken Capone confirmed that the topics of diversity and cultural and linguistic competencies and their relevance are important topics in self-advocacy. Ms. Susan Axelrod added that there might be also group differences among people with I/DD. Mr. Decker responded that the community has to keep pushing for an individualized approach in order to receive an optimal result in this area.

(Afternoon Recess)

AFTERNOON SESSION

Topic #2: Ending Segregation in Education and Beyond

Erik Carter, PhD, FAIDD

Associate Professor, Department of Special Education
Vanderbilt Peabody College

Mr. Dan Habib welcomed and introduced Dr. Erik Carter to the Committee.

Dr. Carter started his presentation by stating that being part of the community is at the heart of what promotes people with I/DD to flourish. He added that it would be impossible to recognize the talents and contributions of people with I/DD, if people never cross path in schools, workplaces, and communities. He expressed belief that “ending segregation is just as much about fostering relationships.” Dr. Carter described that one of the powerful opportunities for the PCPID is to direct systems in our society to understand what it means to be an inclusive community and that people with disabilities are not merely integrated, but they are known and valued and seen as indispensable.

Dr. Carter explained that it is clear that many people with ID are living at the margins of their communities and the national commitment to promote inclusive communities is not penetrated proactively in widespread ways. He said that segregated lives do remain the rule rather than the exception. Dr. Carter shared some statistical data with the Committee members; for example, only 17% of students with ID spend almost all of their day in general classrooms. For students with the most extensive service needs only three percent of those students spend most of their day in general education classrooms. The other 57% spend almost all of their day in segregated classrooms or different schools all together. This means that more than 50 million students, without the labels of disabilities, never have the opportunity to meet or get to know their classmate with I/DD.

Dr. Carter stated that there is clearly a gap between aspiration and experience when it comes to post-secondary education opportunities for students with ID. Only 15% of students with ID enroll in post-secondary education within two years after leaving high school. Two years after leaving high school, one out of four people with disabilities were working; half of whom were working in sheltered workshops or segregated settings. This means that the employees of the 28 million businesses around the country are not getting the chance to meet and work alongside of people with disabilities.

Dr. Carter further explained that for many young adults with ID, their faith is important for their own thriving. According to a recent survey in Tennessee, less than one half of adults with ID who are receiving state-level services were involved in a religious service. Moreover, about half of all high school students with ID have a transition goal to live independently in their respective communities. According to parents of high-school-aged students with ID only one out of five youths frequently see friends outside of school. Two fifths never or rarely receive phone calls from a friend. Data from 2014 reveals that one out of four has never been invited to another person's social event.

Dr. Carter stated that ending segregation in schools is one pathway to having a ripple effect in terms of having employers who are excited about hiring people with disabilities, because they are aware of their abilities. Dr. Carter concluded his presentation by suggesting the following points:

- Our culture needs a fresh call; our professionals need new employment policies
- New policies and practices can make a difference in the lives of people with disabilities
- State-by-State variations need clarity and guidance on principles of the least restrictive environments
- The communities have to learn how to support inclusion of people with disabilities well
- Starting early is the best catalyst that predicts later inclusion of people with disabilities

Ending Segregation in Education and Beyond (Self-advocacy)

Julia Bascom

Deputy Executive Director

Autistic Self Advocacy Network (ASAN)

Ms. Liz Weintraub welcomed and introduced the next guest speaker, Ms. Julia Bascom.

Ms. Bascom began her presentation by addressing what would inclusion look like after an individual with disability has left the education system, once the person turns the age of 21, and how inclusion can influence the person's life after 21. She added that self-advocacy leads to self-determination. Self-determination means that an individual with disability is the one making decisions and determinations about his or her life and receive support, when necessary. Ms. Bascom shared a quote by Ms. Judy Heumann, a disability advocate and author:

Independent living is not doing things by yourself. It is being in control of how things are done.

Ms. Bascom provided three real-life stories about self-determination and inclusion in the community. She added that community inclusion includes housing, self-direction, employment, support and leisure activities, and meaningful relationships. Ms. Bascom explained that "community envision" is very important. She said that the Centers for Medicare & Medicaid Services (CMS) recently has taken this direct approach to look at the qualities that each individual offers and, more importantly, if communities support people with disabilities in making decisions, build relationships, and be in charge of their own lives. To sum up, this is all about life and not about a set of services. She further described how these efforts start with developing high expectations for people with I/DD and getting to know their lives in many ways.

Ms. Bascom talked about how individuals with I/DD deal with a system that "funnels" them up or restricts them in their transition process and planning. This often starts with a complicated Individualized Education Program (IEP). When individuals with I/DD turn 18 years old, their families are being told that they need to participate in IEP meetings and that they should take "guardianship" over the individuals. Therefore, young adults with I/DD will automatically "funnel" into a guardian track rather than having other alternatives available to them. These types of low expectations create segregated settings such as group homes. Thinking outside this "funnel" requires creativity and determination. Ms. Bascom encouraged the PCPID members to think about how to make good lives for people with disabilities. She expressed belief that the reality is that people's quality of life (e.g., civil rights, safety, employment, relationships, etc.) is consistently better in community than in segregated settings.

Q&A Session: Presenters-Committee Dialogue

PCPID Members and Guest Speakers

Mr. Michael Strautmanis thanked the presenters and described that everyone's story is unique based on the disabilities that they are experiencing in an individual-level. He encouraged the PCPID members to try finding the right balance in their work and to create options for people with I/DD based on their individualized needs and future plans. Ms. Bascom said that the Committee is in a position to look across the country to find out what is working for people with different forms of disabilities and to build on the knowledge gap on a national-level.

Ms. Susan Axelrod stated that she really loves hearing real life success stories that were shared with the Committee by the invited presenters. She added that she is happy to learn there are many individuals with I/DD who have chosen and are successfully living in the community. Ms. Axelrod stated that she endorses community living. However, she also endorses and loves where

individuals with certain abilities, just like her own daughter, choose to live—this can be a campus or as some people may call a gated community. Ms. Axelrod added that she will fight very hard to continue her daughter’s ability to live where she chooses to live. She expressed belief that a campus or a gated community should also be considered and that the primary concern should be the quality of life for people with I/DD. Needless to say, quality of life can also be judged by different people in various ways. Ms. Axelrod expressed belief that it is somewhat presumptuous and difficult to assume that we know for everybody what is the highest quality. She shared her daughter’s success story with the members. Ms. Axelrod’s daughter lives in the middle of Chicago on a campus setting, where she absolutely enjoys living and has over 600 friends. Ms. Axelrod restated that she believes people should have choices in their lives and that the primary concern should be to ensure their quality of choices.

Mr. Zach Holler shared a personal story about the time that he was still in high school. His friends separated themselves from him because he had an adult aide or staff assistant. He asked Dr. Carter if there has been any research study conducted in the United States to compare students’ performance independently and with the assistance of an adult aide. Dr. Carter responded that a recent study conducted by the “Institute for the Study of Exceptional Children and Youth” compared students who paired with a professional support versus students who worked under the guidance of a peer support. The results of the study showed that students with disabilities who worked alongside their peers were more academically engaged and made significant progress through their IEP goals, and had five times more social interactions with their classmates (students with or without disabilities). Mr. Davis stated that more visibility and opportunities for interaction will help challenge segregation, prejudice, and false assumption about people with disabilities.

Ms. Pugh asked the presenters about the importance of a “zip code” in determining the degree in which people experience an important inclusive life, and what are some recommendations worthy of exploration. Dr. Carter responded that “calls for research on particular issues about how communities are impacted” would be a good recommendation. Ms. Bascom added that asking for family support funding, and for connecting parents of kids who are newly diagnosed with I/DD can be another area of recommendation worthy of exploration.

Topic #3: Self-Determination and Supported Decision-Making (Self-Directed Life)

Robert Dinerstein, JD

Professor of Law

Associate Dean for Experiential Education

American University, Washington College of Law

Dr. Sheli Reynolds welcomed and introduced Dr. Dinerstein to the PCPID members.

Dr. Dinerstein began his presentation by sharing several real-life stories to illustrate the importance of self-determination and a self-directed life. He stated that self-determination is a power, which identifies adult life in presenting situations and it not only requires decisions to be made, but also helping the individuals to receive help in making sound decisions. Dr. Dinerstein added unless individuals can make certain decisions by themselves without assistance, they

cannot be self-determined and for people with cognitive disabilities making independent decisions is not always the case. An important piece of self-determination is “choice.” Another piece is “consent,” which is a process to allow a person to decide based on information that is provided to him/her that the person understand without coercion.

Dr. Dinerstein shared with the members that one of the earliest mentions of the self-determination and importance of choice and consent came from the Executive Order of the PCPID in 1990’s. The Committee specifically states that there should be national goals to recognize the right of people with ID to self-determination and autonomy to be treated in a non-discriminatory manner and exercise meaningful choice of support. These national rights should recognize the rights of people with ID to enjoy quality of life that promotes independence and self-determination and their participation as the productive members of the society. Dr. Dinerstein encouraged the members to reassert the importance and validity of self-determination.

Moreover, Dr. Dinerstein stated that the American Association on Intellectual and Developmental Disabilities (AAIDD) and the Arc of the United States have issued policy briefs with regards to the importance of self-determination for people with I/DD and their control choices over important aspects of their lives. It is also true that people learn from their mistakes or poor decisions that they may make in their lives. The ADA, the Developmental Disabilities Assistance and Bill of Rights Act, and the Rehabilitation act and other critical statutes have provisions that illustrate the importance of self-determination and autonomy. The society should protect people who are deemed to need protection in making decisions about their lives.

Dr. Dinerstein also mentioned that it is important to start the self-determination process at an early age. There is a huge conceptual difference between advocacy and guardianship. Even if a guardian is guided by the preferences of the individual, the guardian will be making the final decision for that person. A key provision of Convention on the Rights of People with Disabilities (i.e., Article 12) is that some people with disabilities need supported decision-making to exercise their legal capacity.

Morgan Whitlatch, JD

Senior Attorney

Quality Trust for Individuals with Disabilities

Ms. Betty Williams welcomed and introduced Ms. Morgan Whitlatch to the Committee.

Ms. Whitlatch started her presentation by providing a technical definition for supported decision-making, which is “supports and services that help an adult with a disability make his or her own decisions by using friends, family members, professionals, and other people he or she trust to: help understand the issues and choices; ask questions; receive explanation in language he or she understands; and communicate his or her own decisions to others.”

Ms. Whitlatch also shared some of the legal cases from the states of Pennsylvania and Virginia, including the *Ross v. Hatch* case (Va. Cir. Ct. 2013). The Jenny Hatch case is notable because it was a case involving a petition for permanent guardianship that was plenary (meaning that the guardian has control over all aspects of the person’s life). With the help from experts at the Quality Trust in Washington, D.C., Jenny Hatch argued that she did not need to have general

guardianship and therefore the judge ordered a temporary limited guardianship that lasted for a year. This case promoted the idea of using the supported decision-making within the guardianship. Ms. Whitlatch added that her agency was able to create "[The Jenny Hatch Justice Project](#)" and also form a national resource center that is dedicated to improving the knowledge and use of supported decision-making in terms of policy changes. For example, schools in District of Columbia in recent year have started to recognize the supported decision-making as an alternative to guardianship for adult students with disabilities. Furthermore, the resource centers in some states (e.g., Indiana, Maine, Wisconsin, and North Carolina) work to increase the knowledge on supported decision-making on a state-level.

Ms. Whitlatch stated that Ryan King and Susie King (Ryan's mother) will be presenting before the Committee shortly and are planning to talk about their first-hand experience with supported decision-making. She added that Ryan's father (Herbert King) believes that "Ryan is a whole person and decision process is part of what makes someone to be a whole person." Ms. Whitlatch explained that the estimated number of adults under guardianship has tripled since 1995 and studies have shown that in the majority of guardianships, the guardians have control over all aspects of the person's life. She expressed belief that people should be able to exercise their individual rights and stated that guardianship can result in decreased quality of life; and in contrary, increased self-determination leads to improved quality of life. Ms. Whitlatch, as a Senior Attorney, described that the community needs a means of increasing self-determination, while still providing support to individuals with disabilities. She then asked Ryan King to talk about his personal experience with supported decision-making and how the process has worked for him so far.

Ryan H. King

Self-Advocate, Project ACTION!

Ms. Morgan Whitlatch welcomed and introduced Ryan and Susie King to the PCPID Members.

Mr. King shared with the members that he always wanted to be an entrepreneur and to own a limousine and/or travel Services Company. He stated that he is currently working to have a power of attorney that would allow him to make his own decisions. Mr. King is currently practicing money management and volunteers his time at the community services to help other people with disabilities to enhance their self-esteem and interpersonal skills.

Mr. King works for Safeway grocery stores in Washington, D.C., where he has been able to hone his professional skills for the last 14 years. He shared the descriptions of his responsibilities at work and at home as an independent person with the PCPID members. Mr. King said that these tasks have helped him to be a good thinker and allowed him to make his own independent decisions and not be afraid of taking risks. He expressed belief that he always learned from his mistakes.

Q&A Session: Presenters-Committee Dialogue

PCPID Members and Guest Speakers

Dr. White-Scott asked about the legal recognition of the supported decision-making that enables individuals to make their own decisions. Ms. Whitlatch responded that statutory recognition

would be simply great; however, Texas is the only state to recognize supported decision-making. She expressed belief that the “case laws” could be ways to empower the supported decision-making.

Mr. Thornton raised concerns that guardianship could be used a factor to prevent people with disabilities to get married and/or raise their own families. Ms. Pugh asked the presenters about the role of federal government, President and his Administration with regards to the supported decision-making. Dr. Dinerstein responded that the Uniform Law Commission (not a government agency) meets twice a year to make national amendments and/or changes to these laws without going to all 50 states, individually. He added that it is important to know that guardianship “without the opportunity for alternative” might be considered as a violation of the integration mandate of the ADA and the Olmstead Decision. Unfortunately, many agencies rely on guardianship without realizing that there are other choices available to individuals with disabilities.

Ms. Whitlatch stated that her agency (i.e., Quality Trust for Individuals with Disabilities) believes that the CMS quality control and person-centered planning should incorporate principles of supported decision-making at the core of their efforts in order to support all individuals with I/DD properly.

Recapping the Day’s Discussions and Providing Guidance and Directions
PCPID Chair

Chairwoman Julie Petty thanked all the guest speakers for sharing their up-to-date knowledge with the PCPID members. She encouraged the members to think about what they learned from the presenters and be ready to discuss what is the most important topic that will make the biggest impact in the lives of people with I/DD and their families in 2016. Commissioner Bishop added the Committee will have some time for discussions around the final topic and can take its time to develop short statements and preliminary recommendations in the future meetings.

(Recess)

DAY TWO (November 10, 2015)

Call to Order

Julie Ann Petty, PCPID Chair

The November 10, 2015 meeting was called to order by Chairwoman Petty.

Presentation on the Potential Topic

PCPID Chair

Chairwoman Petty provided a presentation to the members regarding the overall topic areas, three possible focus areas, and organization of the next steps and discussions. She indicated that the cultural diversity and civil rights for individuals with ID are overall threads that are inter-related. Chairwoman Petty suggested the following focus areas for the 2016 RTP:

- **Discrimination:** Equality for people with ID from all diverse backgrounds
- **Segregation:** Integration and full inclusion in educational system and beyond
- **Oppression:** Self-determination and supported decision-making

Chairwoman Petty shared with the members that PCPID staff have arranged for small group discussions and encouraged the groups to discuss the following questions:

Question #1: Why the topic in mind is relevant?

Question #2: What are some of the federal policy recommendations for the focus areas?

Question #3: What federal guidelines could be recommended to impact change in states?

Question #4: Who are some national experts in the chosen areas to be invited to PCPID?

Several self-advocate members of the Committee expressed concerns with using the terms “segregation” and “oppression” due to their negative connotations. Dr. Spitalnik explained how all the suggested topics could be framed as human right issues in terms of liberty and decision-making and not oppression. Ms. Gina Kline agreed and stated that all the PCPID future recommendations can be embedded in the context of the ADA requirements.

Formation of Workgroups

PCPID members were divided into the following workgroups to discuss the above-mentioned four (4) questions:

Group #1: Jack Brandt, Speed Davis, Dan Habib*, Zach Holler, Yvette Rivera, Ricardo Thornton, and Betty Williams

Group#2: Micah Fialka-Feldman, Mary Kay Mauren, Stacey Milbern, Deborah Spitalnik*, Michael Strautmanis*, Corinne Weidenthal, and Sheryl White-Scott

Group#3: Susan Axelrod, Lisa Pugh*, Gina Kline, Jeanine Lafratta, Sheli Reynolds, and Liz Weintraub

*Workgroup Spokesperson

Workgroup Report Out

Group #1: Dan Habib reported,

- Ending segregation in education and beyond was suggested as the potential topic by many of the workgroup members
- Address the topic of supported decision-making in the 2016 RTP
- Concerns about civil rights – incarceration and prison pipeline; unemployment of people with ID
- End segregation through enforcement of civil rights
- Need to equip education with tools to help people with ID to achieve a self-directed life
- Concerns about referrals of guardianship by schools
- Need to set the bar higher
- Medicaid is a barrier to higher expectations
- Cultural lens must be used across all recommendations and also to address the issue of disproportionality

Group# 2: Dr. Spitalnik and Mr. Strautmanis reported,

- Supported decision-making as a fundamental civil and human right subject– it is a cutting edge subject that contributes to self-direction
- Supported decision-making not always available to people from different cultural backgrounds (issues of cultural diversity and racial justice). Must have cultural models of decision-making
- Ensure that supported decision-making process is broadly available to individuals and families

Group #3: Lisa Pugh reported,

- Supported decision-making concepts need to be understood and implemented by individuals, teachers, and families early on in the process earlier
- Supported decision-making needs to be available throughout the life-span: Children through adults – give adults who are “stuck” opportunities to make different choices
- There is an opportunity to address segregation in education – “new frontier” of the ADA
- Get to families earlier to help them set a new trajectory
- Increase awareness about the benefits of inclusion to society and not just to people with disabilities (i.e., setting the agenda for the new Administration)

Commissioner Bishop restated that the main goal of the day is to come up with a topic for the 2016 RTP. He added that ending segregation in schools was suggested by Workgroups #1 and 2 as the potential report topic. However, Workgroup #3 argues that youth must be involved in decision-making processes from an early age. Commissioner Bishop explained that there should be a way to blend all these points together and keep the human and civil rights aspects of the supported decision-making process in the RTP, and further talk about how to end segregation in schools.

Discussions

PCPID Members

- Merge the Committee's knowledge on segregation of students with ID in schools with its enforcement role that can contribute to self-determination of students with ID
- Create a template for "agenda setting" for a new Administration
- Make sure recommendations can also apply to career employees who will remain in current Administration – even though timeframe is short due to upcoming election
- The future is now – must focus on ending segregation
- People must have basic needs met – before they are able to participate in true supported decision-making
- There is an expectation gap – students with disabilities do not have the supports available to meet their expectations – students must be leading their IEPs – build supported decision-making throughout the process
- What are the resources available to the Committee to accomplish writing the 2016 RTP?

Mr. Habib suggested the following four (4) focus areas for the 2016 RTP:

Focus Area #1: Family engagement early on in the process to support high expectations for students with disabilities

Focus Area #2: Federal education policies and enforcement strategies to end segregation in schools

Focus Area #3: Transition as a critical area for pathways to higher education and career development

Focus Area #4: Self-determination/Supported decision-making from early childhood throughout the individual's lifespan

Consensus Points:

PCPID Members

- Individual dignity for people with ID– need structures and training in place to give people tools and best practices to accomplish supported decision-making
- Everyone should be able to make individual decisions in their own lives
- Get at civil rights and segregation through a focus (with an intentional cultural lens) on increasing supported decision-making
- Start with young ages – at the beginning; starting early means everything
- The burden should not be placed on families; what is the role of government? – require role for Government to facilitate change
- Decisions matter
- Young people must be involved in charting their own course/changing the trajectory
- We cannot be true to people's power and choice if there is segregation in schools
- We must focus on ending segregation in schools
- Concerns about phrase "starting early" (excludes older adults)
- Concerns about lack of focus for Committee work – this cannot be too broad
- Concerns about narrowness of supported decision-making focus – discuss ability to embed concepts of supported decision-making

Consensus Theme (This is not a title of the report):

The Committee voted and agreed on the following theme for the 2016 RTP:

- **Starting Early: Supporting (Facilitating) People with Intellectual Disabilities and their Families to Demand a Different Trajectory**
(by embedding stronger self-determination , choice-making for youth with I/DD)

To include older adults, this can also read: Supporting People with Intellectual Disabilities **of all Ages**: Providing Necessary Supports and Policies to Demand a Different Trajectory

Summary of Deliberations, Proceedings, and Next Steps

Julie Petty, PCPID Chair

Chairwoman Petty thanked the PCPID Members for reaching a consensus on the theme of the 2016 RTP. She stated that the PCPID staff will be in touch, via e-mail, to complete the process of developing the workgroups in the following areas:

- **Family engagement** early on in the process
- **Federal education policies and enforcement strategies** to end segregation in schools
- **Transition** as a critical area for pathways to higher education and career development
- **Self-determination and supported decision-making**

Meeting Adjournment

PCPID Chair

Chairwoman Petty made the motion to adjourn. Ms. Weintraub and Mr. Thornton seconded the motion. The meeting was adjourned.

ACTION ITEMS:

PCPID Members

1. Submit travel expenses to the PCPID Program Assistant for reimbursement purposes five business days after the meeting. (Completed)
2. Share all new ideas about the PCPID Wiki (e.g., guiding questions) with the Committee's Team Lead within the next two weeks after the meeting. (Completed)
3. Complete the meeting "Evaluation Survey" by **Friday, November 20, 2015**. (Completed)

PCPID Staff

1. Share a short summary of the meeting proceedings with all members by **Monday, November 23, 2015**. (Completed)
2. Convert the meeting recordings into minutes by **Friday, December 18, 2015**. (Completed)
3. Locate and share with the members the most recent national reports on prison pipeline and criminal justice system for people with IDD. (Completed)
4. Share the PCPID Wiki scripts with the volunteer members and finalize the scripts by **Tuesday, December 1, 2015**. (Completed)
5. Reach out to the members to establish new workgroups prior to the next meeting of the Committee. (Completed)