



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

Committee Meeting
February 22-23, 2016
~Draft Minutes~

Citizen Members

Julie Petty, Chair
Peter Berns
Jack Martin Brandt
Jim Brett
Kenneth Capone
Micah Fialka-Feldman
Dan Habib
Zachary W. Holler
Stacey Milbern (via telephone)

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

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 (via telephone)
Representing the Honorable Penny Pritzker
Secretary, U.S. Department of Commerce

Richard Davis for Jennifer Sheehy
Representing the Honorable Thomas Perez
Secretary, U.S. Department of Labor

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

Sue Swenson and Corinne Weidenthal, EdD
Representing the Honorable Arne Duncan
Secretary, U.S. Department of Education

Brian Parsons (via telephone)
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

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

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

Gary Blumenthal
Representing the Honorable Clyde E. Terry
Chair, National Council on Disability

Special Guest Speakers and Presenters

Judith E. Heumann
Special Advisor for International Disability
Rights
U.S. Department of State

Michael Gamel-McCormick, PhD
Associate Executive Director for Research
and Policy
Association of University Centers on
Disabilities (AUCD)

Larissa Crossen
Program Specialist
Administration for Community Living
(ACL)
Administration on Intellectual and
Developmental Disabilities (AIDD)

Ophelia McLain, DHA
Director
ACL-AIDD

Carol Quirk, EdD
Executive Team of the SWIFT Center
Executive Director
Maryland Coalition for Inclusive Education

Serena Lowe, PhD
Senior Advisor
ACL-Center for Disability and Aging
Policy (CDAP)

Eric Weakly, MSW, MBA
Aging Services Program Specialist
ACL-CDAP

Molly Burgdorf, JD
Senior Advisor
ACL-CDAP

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, ACL-AIDD

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

Sheila Whittaker
PCPID Program Assistant

Meeting Proceedings

DAY ONE (February 22, 2016)

Greetings and Introduction of PCPID Chair

Aaron Bishop, Commissioner
Administration on Disabilities (AoD)
Designated Federal Officer (DFO)
President's Committee for People with Intellectual Disabilities

On behalf of the U.S. Department of Health and Human Services (HHS), Commissioner Aaron Bishop welcomed participants and thanked PCPID members for joining the meeting. He shared with the members that this full Committee meeting will follow a special agenda, which includes several inspirational guest speakers and presenters. Commissioner Bishop stated that the meeting presentations are designed to assist the members with overall preparation of the 2016 Report to the President (RTP). He, then, turned the meeting over to the PCPID Chairwoman, Ms. Julie Petty.

Welcoming Remarks, Call to Order, and Introductions

Julie Ann Petty
Chair

The PCPID Chairwoman, Ms. Julie Petty, welcomed participants and called the meeting to order. She requested all members to introduce themselves and identify their affiliations with the Committee. This was done in a "round robin" format.

Approval of Agenda and Minutes (November 9-10, 2015) PCPID Chair and Members

Chairwoman Petty made the main motion to approve the minutes of the PCPID November 9-10, 2015 meeting. Ms. Liz Weintraub and Mr. Ricardo Thornton seconded the motion to approve the minutes of the last meeting. Chairwoman Petty also made a motion to approve the meeting agenda, which was seconded by Ms. Lisa Pugh and Mr. Michael Strautmanis. The Committee voted to accept the minutes as well as the meeting agenda. Motion carried.

PCPID Guest Speakers

Commissioner Bishop introduced the first guest speaker, Ms. Judith "Judy" Heumann, who is the Special Advisor for International Disability Rights at U.S. Department of State. He referred to Ms. Heumann as "a living legend" in the field of disability. Commissioner Bishop added that Ms. Heumann was invited to share her experience with the Committee on disability data both at a national and international level.

Judith E. Heumann

Special Advisor for International Disability Rights, U.S. Department of State

Ms. Heumann started her presentation by thanking the PCPID members for the work they have done for years as well as giving her the opportunity to share the changes, occurring in the field.

She added that PCPID is one advisory Committee that is cutting-edge and is a risk-taker. The Committee has helped guiding the path for future of disability policies for many decades.

Ms. Heumann took the members through a short history of disability legislation. She stated that the 1960s were when the nation began to see disability legislation move forward. By the late 1960s, the United States (U.S.) also experienced the first federal law, addressing the issue of accessibility and the establishment of the U.S. Access Board. In the 1970s, the nation saw more progress with the passage of Title V of the Rehabilitation Act, and the provisions in the Rehabilitation Act of Independent Living, the Education for All Handicapped Children's Act, and the regulations for Section 504. Ms. Heumann expressed belief that one of the dynamic changes over many decades is the role that people with disabilities, themselves, played in advancing the disability rights movement. This is important, because the primary voices in the field should be made by people with disabilities from all walks of life.

Ms. Heumann noted that it is pivotal to create a society where there is an expectation that all individuals are living and are integrated in the community, and receive proper services and support. It is critically important that people with disabilities live in their communities amongst their peers; and their peers should not necessary be others with disabilities. She stated that the Convention on the Rights of Persons with Disabilities (CRPD) is a valuable resource and was modeled after the Americans with Disabilities Act (ADA). Unfortunately, there is a significant amount of discrimination that goes on in various countries around the world, which is developed by the low expectations from people with disabilities and their families.

Ms. Ms. Heumann reiterated that the role of PCPID is to take the lead on supporting community-based initiatives; helping families to be able to keep their children at home; and enabling individuals to continue to reside in their communities. In a number of countries around the world, there are restrictions regarding the parents' involvement, employment, and higher-education and use of technology. This is while people with disabilities comprise 15% of the world's population.

Open-Forum Discussion

Presenter-Full Committee

On behalf of the Committee, Mr. Gary Blumenthal thanked Ms. Heumann for her continued support of PCPID in the last twenty years. Ms. Heumann expressed gratitude and added that in the U.S., many agencies collaborate on the disability issues. However, she noted that regrettably most immigrants with disabilities in the U.S. are not being appropriately served by many agencies. We cannot automatically expect that people who have just immigrated to the U.S. will have no problem understanding our laws on education and community living, and easily pursue their dreams which otherwise they would never have been able to exercise in their own countries.

Ms. Liz Weintraub noted that one of the struggling areas for people with disabilities is inclusion—especially, inclusiveness in education, employment and career development. Mr. Dan Habib stated that the community still views special education as a place, and not a set of support, and does not fully recognize that general education is for every student. Some other problems are that the community believes parents are responsible to enforce the Individuals with Disabilities Education Act (IDEA). Also, the communication supports are not being introduced to students at an early age. The communication assessments are not part of the individualized education plan (IEP) process, so young students with disabilities do not have a voice from very

early on, and then the low expectations follow because they think they have nothing to say. Finally, the “teacher training programs” should incorporate universal design of learning, and multi-tiered systems of support (MTSS) as well as positive behavioral support as a requirement. Ms. Heumann agreed and responded that unfortunately these issues are still sensible in 2016. It is important to benchmark communities that do well in implementing a creative work; especially, on the issues revolving around dropout rates in students from a diverse ethnic and socio-economic background.

Mr. Jim Brett asked the guest speaker if she had specific suggestions for topics that PCPID should consider. Ms. Heumann replied that it is important to get the message out that people with significant disabilities deserve proper education with high expectations, and they have choice in type of education and employment they choose to pursue. Dr. Deborah Spitalnik noted that the state of New Jersey supported many immigrant families who were not able to receive services in their own countries. The communities in the U.S. also need an education system where those who provide supports reflect the communities that they serve. Ms. Heumann agreed and added that the Department of State encourages ambassadors to hold roundtables with civil society organizations to learn more about the situations in their countries and get a better sense of weaknesses that exist in their countries. The U.S. Congress also requires submission of the “Human Rights Report,” which is done in every country and section six of the report refers to disability policy work. The Human Rights Watch, as U.S. based organization, meets with governments, the United Nations, regional groups like the African Union and the European Union, financial institutions, and corporations to press for changes in policy and practice that promote human rights and justice around the world.

Mr. Ken Capone shared with the Committee that Maryland’s Self-Advocacy Group submitted legislation to phase out sheltered workshops and set minimum wage. Mr. Richard Davis thanked the guest speaker for challenging the Committee to be cutting-edge and to confront issues revolving around low expectations, the segregations that result from racism, and societal attitudes around so called “ableism.” Ms. Sue Swenson stated that the CRPD requires the governments to support organizations that provide services to people with disabilities within various nations and call for collaborations at an international level. She asked if it is possible to go forward without ratifying to support and fund some of these initiatives and simply connect to Disabled People Organizations (DPOs). Ms. Heumann responded that the Article 32 in this Treaty addresses the importance of inclusiveness in the field. Both the Department of State and United States Agency for International Development (USAID) are taking the lead on the efforts that ensure integration of disability services into grant-making mechanisms. Meanwhile, they engage in stronger advocacy, law training, and leadership development. She added that regrettably the current reorganization of the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) would prevent this agency to use the Office of Special Education and Rehabilitation Services’ authority to engage in international disability work.

Michael Gamel-McCormick, PhD

Associate Executive Director for Research and Policy
Association of University Centers on Disabilities (AUCD)

Dr. Gamel-McCormick began his presentation by sharing a personal story from the time when he was an educator in early childhood education and intervention. He shared this story to emphasize the importance of the “Zero Reject” that is embedded within the Education for All

Handicapped Children Act of 1975. The Zero Reject states that nobody should get excluded from education. Another important area of the 1975 Act is the “Least Restrictive Environment.” It is crucial to be connected to communities, neighborhoods, and people who we live with on a daily basis. Dr. Gamel-McCormick added that the No Child Left Behind uncovered what was happening with subgroup of students: a) those who were English learners, living in poverty, and b) those of different races and ethnicities, and disabilities throughout the country. One of his group research studies of the No Child Left Behind showed that two factors predicted outcomes for younger learners: 1) inclusive education (if they were enrolled and connected with their developing peers), and 2) if they had early intervention and early childhood education. Dr. Gamel-McCormick noted that “inclusive” is not a program; it is a philosophy and approach to education overall. He shared with the members that in the reauthorization of Every Student Succeeds Act ([ESSA](#)) that took place in December 2015, there are 106 mentions of students with disabilities in the general education. He added that the indicator of high-school graduation rates in 2001 compared to high school graduation rates in 2013 for students with disabilities increased 16 percentage points. So, with high expectations for students, educators can get them the resources they need to achieve great things in life.

Open-Forum Discussion Presenter-Full Committee

Ms. Lisa Pugh specified that unfortunately students with the most significant intellectual disabilities (ID) still experience a tremendous amount of segregation in school; particularly, in high school level. She emphasized the importance of parental involvement, because there is body of research illustrating that when parents have higher expectations, their child is three to five times more likely to experience high success rates in education, community living, employment, and other aspects of adult life. Ms. Pugh asked the guest speaker: a) what are some factors that can contribute to parents’ engagement and for them to build high expectations? and b) is it unethical to build up the high hopes and visions, if the adult system is not ready for inclusiveness? Dr. Gamel-McCormick responded that the “Promoting the Readiness of Minors in Supplemental Security Income (PROMISE) Initiative” is currently being implemented in six localities around the country and part of this initiative is to work with families about expectations and their possible outcomes. He expressed personal belief that it is only unethical “not to talk about the expectations.” Mr. Zach Holler agreed and also added that on a different note, there is not a one-size-fits-all approach when it comes to integration in special education— nothing that will work for all districts (i.e., reverse mainstreaming or reverse inclusion). Ms. Yvette Rivera stated that one other important factor to consider is to provide “implementation tools,” because a community can have all the best policies in the world; however, with no proper implementation strategy there will be no optimal outcome.

Announcements

Commissioner Bishop shared with the members that the Committee has been invited to provide presentations on its 2015 Report to the Federal Communications Commission in March, the American Network of Community Options and Resources ([ANCOR](#)) Conference in May 2016, and finally a briefing to the members of Congress will be scheduled.

Dr. MJ Karimi, PCPID Team Lead, introduced all the federal panel invitees who were scheduled to provide presentations on their recent initiatives, and to share project data, analysis and interpretations.

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

Data Analysis, Interpretation, and Presentation

Larissa Crossen, ACL-AIDD Program Specialist

Ms. Larissa Crossen started her presentation by providing an overview of the family support initiatives that the AIDD has funded since 1999. Through the Project of National Significance (PNS), the AIDD awards grants/contracts that enhance independence, productivity, inclusion and integration of people with I/DD into the community. What fell under PNS is also the Family Support 360 (i.e., Family Support and Community Access). Between 1999 and 2004, the AIDD awarded 54 family support projects, nationwide, to support families of individuals with I/DD. In 2004, the agency awarded the first of five grants on planning and implementation of the projects to 21 entities. Between 2004 and 2009, AIDD had the Family Support 360 Centers as well as the military centers; another funding opportunity was also granted in 2010 to five initiatives on Family Support and Community Access.

Ms. Crossen stated that families, through navigators at one-stop-shops, could identify services and support based on their individual needs. For military families, the navigator has helped to bridge the gap between military and civilian systems. Additionally, the family support community access projects focus on systematic change and target specific communities to engage in capacity building. For example, some areas of work in previous years were to establish individual development accounts for people with I/DD, provide supports to fathers and grandparents, and other non-traditional caregivers. Some other accomplishments involved working with the school systems to develop and improve programs in IEPs, offering support to families, whether it was food, clothing, transportation, or anything that was identified during the IEP process. Finally, the AIDD funds the Community of Practice (CoP) for Supporting Families of individuals with I/DD. The overall goal of the CoP is to support families so they can support, nurture, love, and facilitate opportunities for achieving self-determination and independence throughout the individual's lifespan.

Dr. Sheli Reynolds reported that the Title II of the DD Act calls for funding of the family support projects. She added that when family support initially started out, it focused on the system change initiatives. Then, it moved to target populations that were underserved as well as the military families. Recently, the ACL-NIDILRR has funded the University of Chicago, Illinois, to focus on research on family support. The Committee should ensure that this research will include individuals with I/DD and their families. Dr. Reynolds stated that many of the national initiatives or demonstration projects have been outside the purview of the state service systems. The National Association for State Directors for Developmental Disabilities Services has therefore recognized the need for partnerships to bring the work of family movement with the work of the state structure together.

Dr. Reynolds explained that the first couple of AIDD grant years were spent on creating a common language. The concept of "families' life course framework," was established through these grants. It enabled all stakeholders to have conversations at a policy-level and based on one-on-one planning with individuals and families. Dr. Reynolds noted that the Health Resources and Services Administration (HRSA) funds the family-to-family health informatics centers. Currently, there is zero funding for family support initiatives and specifically for

families that have adult children with I/DD. This is despite the fact that 87% of adults with intellectual disabilities (ID) and/or other developmental disabilities (DD) live in a family home.

Ophelia McLain, DHA (on behalf of Katherine Cargill-Willis, AIDD Program Specialist)
ACL-AIDD Director

Dr. Ophelia McLain stated that, in 2011, the AIDD awarded funds to the University of Minnesota (UMN) for a five-year cooperative agreement to ascertain the longitudinal data in the areas of employment and residential settings for people with I/DD. The Family Information System Project ([FISP](#)) is currently looking at: a) how many people in the states are using publicly-funded services while living at home with family members, b) how many people are on the waiting list, and c) how much is being spent by the states on the residential settings of people with I/DD. Research by the UMN revealed that 61% of people with I/DD live at home that they own or lease, 12% live in some other settings such as foster home or host home, and 51% live in a shared by three or fewer people with disabilities. In 2013, 700,000 individuals were Medicaid recipients and approximately 175,000 of them were children or youth (21 or younger); over 500,000 individuals were adults with I/DD (22 years or older). Nearly, 88% of individuals younger than 21 lived in the home with a family member, and 12% lived in some other setting such as foster or group homes. Many received waiver-funded supports in the home of a family member.

Dr. McLain further suggested and explained why the National Health Interview Survey (NIHS) should include questions about I/DD for both children and adults, update prevalence estimates for I/DD (e.g., Autism Spectrum Disorder) every year, and stay current with information about individuals with I/DD who are not receiving Medicaid LTSS.

Open-Forum Discussion

Workgroup Members, Data Analysis Team, Full Committee

Mr. Blumenthal thanked the presenters and added that every dollar spent on family support reduces the trends of residential services, and with regards to residential services, the cost is becoming quite difficult to sustain within the budget. He recommended that members invite a representative from the Centers for Medicare & Medicaid Services (CMS) to participate in PCPID meetings and discussions. Dr. Reynolds pointed out that the states are becoming creative with their family support waivers, but strict guidelines remain in the process. Mr. Strautmanis encouraged the Committee to collaborate with the [U.S. Digital Service](#) in these areas. Ms. Swenson added that the real approach to digital thinking is to start considering big data, and understand how it is possible to describe people with disabilities without placing them in different categories. The digital strategy could also help advocates to understand how people, themselves, define their functional differences.

Ms. Weintraub raised concerns over the self-advocacy voice that may be overshadowed by families at times. Dr. Reynolds responded that both individual and family voices offer unique perspectives, so they both need to be invited at the discussions table. Dr. Spitalnik agreed and added that building systems of support that transcend the distinctions between school systems and adult service systems play a major role in such cases. Mr. Brandt noted that there are individuals in foster care and other environments where expectations do not really exist. Dr. Reynolds and Dr. McLain expressed belief that family is defined differently and in most cases the definition depends on one's cultural belief.

Ms. Pugh asked about the role of family navigators. “Are they connecting families to disability-specific services for their individual child, or are they connecting families to a broader community and to generic types of services?” Ms. Crossen responded that for the Family Support 360 Centers in the military projects, the basic role of the navigators was to start with identifying or developing a plan—this plan contained all services and support that the family needed either at home or the community. Dr. Reynolds added that the government sector is starting to recognize the important role of the navigators in social services or medical systems. Dr. White-Scott noted that it appears that the communities need data and anecdotally family navigators are out there; however, they might not be known to the general public. Ms. Stacey Milbern encouraged the Committee to also explore the concept of disparity in services through the 2016 RTP.

(Afternoon Recess)

The PCPID Members watched and discussed the preview of a new film by Mr. Dan Habib, entitled “[Intelligent Lives](#)”

AFTERNOON SESSION

Focus Area # 2: Federal Education Policies and enforcement strategies
to end segregation in schools

Data Analysis, Interpretation, and Presentation

Carol Quirk, Ed.D., Executive Team of the SWIFT Center

Dr. Carol Quirk began her presentation by stating that although she works for Maryland Coalition for Inclusive Education, the majority of her time is spent with the [SWIFT](#) Center (K-8), which is the National Center for Schoolwide Inclusive Reform, focused on promoting inclusive practices. One potential outcome of the SWIFT Center is to end segregation of students with disabilities who are placed in more restrictive settings by building state and local capacity. The grant was funded specifically to work in elementary and middle schools to build state and local capacity to provide academic and behavioral support to improve outcomes for all students. The project focuses on students with disabilities, including those with the most extensive support needs. The Center has five state partners: Maryland, New Hampshire, Vermont, Mississippi, and Oregon (64 schools across the country). Within these partner states, the project works with schools and districts. The Center’s philosophy is that, together, the community can transform education so that it benefits each and every student, their families, and ultimately the community.

Dr. Quirk explained that simply being physically present in a general education classroom does not equate to “being included.” She shared some historical pictures of special education classrooms and referred to the level of communication with students at that time. Furthermore,

she expressed that students who lack access to the general curriculum and to their grade level peers are missing out on educational opportunities. The federal laws (e.g., the IDEA) state that special education means specially designed instruction, and later define it as a tool to address the unique needs of students with disabilities. There could be any number of materials, environments, social, emotional or program modifications that are specifically related to that particular disability. The IDEA requires each public agency to ensure that a continuum of alternative placements is available to meet the needs of children with disabilities for special education and related services. Special classes, separate schooling or other removal of children with disabilities from the regular education environment only occurs if the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily.

Dr. Quirk illustrated data regarding the placement of students with disabilities in self-contained settings and made the point that the data has not changed much over the years. A number of researchers have found striking state and regional variations in placement rates for students with disabilities, which suggests that things like zip code may factor into placement decisions. For example, a study (conducted by Kurth) of students with autism found that states that have higher proportion of white citizens and lower poverty rates are more likely to have students placed in an inclusive setting when compared to states with more diversity. Ms. Swenson noted that it used to be true that about 80% of students with IEPs have only one speech or language goal on their IEP. She asked if there are newer data available. Dr. Quirk responded, “unfortunately no.”

Dr. Quirk noted that lately emphasis has been placed on developing tiered systems of support (e.g., Positive Behavioral Interventions and Supports (PBIS), response to intervention, and systems that combine academics and behavior known as multi-tiered systems of support). In order to implement these types of systems, schools need to have benchmark data for reading, math, and behavior as well as formative assessments to monitor progress over time. Research shows that when students with reading disabilities get high-quality general education instruction plus intensive instruction in their reading needs, they improve more than when they have just one or the other. There is no research that shows when students are self-contained, they learn more. Some people may assume that a self-contained setting offers highly qualified instructors; there is no evidence to confirm this point.

Dr. Quirk explained that there are five domains (each has two features) that the SWIFT Center is currently looking to build. These domains are: (1) administrative leadership, (2) multi-tiered system of support, (3) integrated educational framework, (4) family and community engagement, and (5) inclusive policy structure and practice. Ms. Gina Kline asked if there has been any research to evaluate the long-term cost efficiencies of mainstream education as well as the SWIFT model. Dr. Quirk responded that there has not been a cost evaluation in this work. Mr. Habib talked about the importance of having bold ideas. For example, one idea is to get rid of disability categories (i.e., no disability labels) and mainly take into account the support needs of an individual. Another idea is to phase out IDEA, and make it part of the ESSA in order to break the barriers and get rid of silos. Ms. Swenson expressed personal belief that IDEA is extremely clear about inclusive placement; and if that is not possible, one should make a placement decision at that point. This goes back to understanding of what segments of the general population use IDEA, and what are their various concerns on disability categories, zip codes, and other living circumstances.

Open-Forum Discussion

Workgroup Members, Data Analysis Team, Full Committee

Ms. Pugh asked if the “Dear Colleague” letter from the Department of Education can help update the current educational regulations. Dr. Quirk responded that the “Guidance Document” was very helpful. However, different interpretations of it can get in the way. Mr. Richard Davis pointed out the philosophy of the ecology of the classroom, which uses the universally designed classroom to solely respond to the support needs of students and not the differing disabilities. Mr. Thornton asked about the community involvement and strategies for inclusions of students. Dr. Quirk responded some of the critics of moving towards inclusion might be special education teachers and parents who are afraid of their children being hurt. It is important to have an active strategy developed in order to communicate with parents on a regular basis. Mr. Brian Parsons agreed and stated that higher education teacher preparation programs and communication assessments (on IEPs) are also important strategies. Mr. Strautmanis stated that this speaks to the importance of civic engagement that will be impactful—the access that the Committee has to its network, constituents, and other audiences can make an impact in this very important area.

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

Data Analysis, Interpretation, and Presentation

Serena Lowe, PhD, ACL Senior Advisor

Larissa Crossen, ACL-AIDD Program Specialist

Dr. Serena Lowe shared with the Committee that her presentation will focus on: a) explaining several existing federal policies on transition outcomes for youth with I/DD, b) highlighting the AoD-AIDD’s investments on this area, and c) sharing some of the accomplishments of the federal partners. She pointed out that many of the federal investments, in recent years, have been appropriated on school-to-work transition from the platform of employment first, which is the national movement that publicly finance services and support on competitive integrated employment. The “Employment First State Leadership Program” includes coordination, planning, and service delivery and outcome measurements to track the respective progress overtime. It requires methodical resource integration, which can be challenging in the Federal-level. The Department of Labor (DOL) is working around system change with the focus on successful school-to-work transition outcomes. The Pathways to Career Initiative is also conducting rigorous research in the area of transition.

Ms. Crossen continued this presentation by explaining the role of AIDD and its investment in initiatives that focus on youths and successful transition to education and career development. As a part of the requirements, the AIDD has asked its grantees to develop innovative strategies to ensure knowledge transfer and management of best practices between the consortium and state systems on employment for workers with I/DD. She added that some other requirements focused on exploring ways to stimulate the array of service providers and maintaining competitive employment in integrative settings. AIDD also paid attention to developing a method in providing ongoing training and technical assistance to state systems and different provider agencies.

Dr. Lowe stated that this year, the DOL will fund 19 core states that provide direct technical assistance and policy consulting. The Federal government rewards the good work of cross system team-building that is aimed to bring transition coordinators, teachers, vocational rehabilitation (VA) counselors, and I/DD case managers together to implement effective practices. The government also provides ongoing mentoring and professional coaching overtime so that as people are applying this work on a local-level, they receive supports needed to strengthen their work. The PROMISE Initiative, by far, is one of the biggest investments to bring federal partners together. The Pathways to Careers Initiative is another high profile project. With regards to the Workforce Innovation and Opportunity Act (WIOA), the federal investments and commitment to youth and youth with disabilities create some opportunities along the way. According to Title I of the Act, local youth formula funds have to use at least 20% on creating work experience for youths, including partnerships, job shadowing, summer and year-around employment. In addition, 15% of all VR funds have to be used for transition services including work-based learning experiences.

Dr. Low continued her presentation by saying that with workforce development systems (American Job Centers), 75% of local formula funds have to be focused on out-of-school youth up to age 24. There is also a major focus on performance, in WIOA, in measuring and evaluating process in both the VR and workforce investment systems. The WIOA will require a cooperative agreement between the state's VR system and state Medicaid and I/DD agencies. Section 511 in Title IV of WIOA limits the conditions that individuals 24 or younger, through VR system, could be placed into a recommended and/or referred sub-minimum wage work. WIOA youth services is an opportunity for great partnerships and collaborations across the multiple systems. Additionally, the topics such as building and sustaining the capacity among direct support professional and effective practices; misunderstanding employers and holistic wrap-around services; and performing stakeholder engagement with fidelity are very important.

Open-Forum Discussion

Workgroup Members, Data Analysis Team, Full Committee

Ms. Weintraub asked what would happen to the PROMISE grant after the five-year contract. Dr. Corrine Weidenthal responded that the Department of Education will have a project review soon to take a look into the sustainability of this project. Ms. Pugh mentioned that there is a certain type of supplementary aid and services that support students before they would be deemed. She showed concerns about the lack of assistive technology evaluation to support individuals in every employment setting. Ms. Swenson pointed out that in 2015, Office of Special Education and Rehabilitative Services funded a \$20 million grant to perform "Automatic Cloud Personalization" in order to build the infrastructure that allows technologies to operate by recognizing the individual's accessibility needs.

Mr. Habib asked if there is any existing funding stream for reimbursement; specifically, for the person-centered planning. Dr. Low replied that the Home and Community-Based Services (HCBS) is the impetus to making sure that individuals receive supports in integrated settings and have maximum access to community living. There are states that in their waivers and state plan options pay for person-centered planning. Ms. Swenson and Mr. Blumenthal raised concerns that many states do not fully unitize their VR dollars, and return the remaining funds to the Federal government.

Recapping the Day's Discussions and Providing Guidance and Directions

Julie Petty, Chair

Aaron Bishop, Commissioner and DFO

Chairwoman Petty announced that the Committee is scheduled to break into four small Workgroups on the second day of the meeting. This is being done to provide an opportunity to members to discuss their selected focus areas in small groups. Commissioner Bishop brought the meeting to an end by stating that the presentations, data, and open discussions helped frame the focus areas of the RTP. He added that the committee will follow the same guidelines as last year to prepare a timely RTP. This will happen before May 11, 2016, in which many of the current members are expected to exit out of the Committee.

(Recess)

DAY TWO (February 23, 2016)

Call to Order

Julie Ann Petty, PCPID Chair

The PCPID February 23, 2016 Meeting was called to order by Chairwoman Petty. She stated that the Committee was scheduled to receive presentations on Self-Determination (SD) and Support Decision-Making (SDM) by the ACL staff.

Focus Area # 4: Self-Determination/Supported Decision-Making from early childhood throughout the individual's lifespan

Data Analysis, Interpretation, and Presentation

Molly Burgdorf, ACL Senior Advisor

Ms. Molly Burgdorf started her presentation by highlighting the ACL's mission and vision statement, which is around maximizing the independence of people with disabilities—a key point that relates to the SD and SDM. Furthermore, the vision of ACL takes into the account all people, regardless of their disabilities and age (referring to the DD Act and Older Americans Act) to live with dignity, make their own decisions, and participate fully in their respective communities. For instance, the Older Americans Act includes freedom, independence, and the free exercise of individual initiative in planning and managing one's own life. The DD Act addresses SD and independence among many other areas. One other mandate under the ADA, administered by ACL, is Olmstead Decision and that is the integration of people with disabilities in their communities. The ACL currently houses NIDILRR and the Independent Living Administration (ILA), and funds the National Resource Center for Supported Decision-Making.

Mr. Eric Weakly added that the ACL's Center for Integrated Programs develops grants and agreements that are cross-disability (across aging, and physical and cognitive disabilities). This year, Syracuse University is working on a small qualitative study to determine how different individuals use SDM. The University also works in collaborations with the Quality Trust for Individuals with ID in Washington, D.C.

Ms. Burgdorf explained the technical definition of the SDM. The SDM is a “recognized alternative to guardianship through which people with disabilities use friends, family members, and professionals to help them understand the situations and choices they face, so that they may make their own decisions without the need for guardians.” Ms. Burgdorf provided reasons for why SDM is important. The SDM protects and preserves individual rights; helps advance the best quality of life for individuals, and put tools in place so that individuals can be supported without burdensome legal measures. Ms. Burgdorf pointed out that the research on the topic of SDM is new. However, the body of research will be growing in the coming years as the results of research in this area show that people are healthier, more independent, more well-adjusted and better able to recognize and resist abuse through the SDM.

People who do not exercise self-determination (SD) feel helpless, hopeless, and are self-critical. Since research shows that SD is good for individual development, the current trends on guardianship look even more troubling. Guardianship is a state-by-state patchwork of law as there is not a federal guardianship statute. However, the number of guardianships issued these days is growing astronomically. The National Legal Resource Center, which is an Older American Act-funded resource for lawyers and other legal providers (e.g., adult protective services) has engaged on SDM and hosted several webinars so far. Additionally, the National Guardianship Association has issued a position statement, recommending SDM as one of the effective options.

Ms. Burgdorf continued by saying that the SDM and SD are also growing in the HHS context. The CMS has encouraged the states to develop systems for HCBS that are supposed to be designed to respond to the changing needs of beneficiaries in maximizing their independence and self-direction. The guidance, issued by the Secretary of Health and Human Services, highlights standards on person-centered planning and self-direction in HCBS and specifically discusses how to access the needed supports in a manner that is consistent with the person’s preferences to achieve a better quality of life.

Mr. Blumenthal asked the presenter: “as CMS encourages LTSS, including its waiver services (and managed care), what can ACL do to reconcile some of the conflicting directions by the CMS.” Ms. Burgdorf responded that at this time, the ACL is engaged in a collaborative process with CMS to review the states transition planning.

Mr. Holler expressed belief that the SDM does not only pertain to ID, but also to DD. Ms. Swenson educated the Committee on intricacies around the Article 12 of the CRPD, which talks about the legal capacity. Mr. Brandt asked if there are any data available on how many people have guardianship who also receive Medicaid or Medicare. Ms. Burgdorf responded that there is no 100% accurate picture of who has or who is under guardianship in the U.S. Mr. Strautmanis encouraged the Committee to urge Federal partners to get rid of the existing silos and work coherently in order to have positive outcomes and to empower individuals and families in guardianship and SDM processes.

Dr. Spitalnik pointed out that one question about the SDM is: “what is the legal back up to it in terms of recognizing decisions that are being made.” She encouraged the Committee to not only recognize the SDM as a basic human right, but also as a civil right issue. Mr. Berns ask if there is a body of research that looks at SD within the context of guardianship. Ms. Burgdorf responded that some preliminary research on this topic might have been conducted this year.

Eric Weakly, ACL-CDAP, Aging Services Program Specialist

Mr. Eric Weakly began his session by talking about the “No Wrong Door,” in relations to person-centered planning and self-direction. He explained that from 2002 to 2004, the CMS and Administration on Aging work together to determine if there was local and statewide coverage for Aging Disability Resource Centers (ADRCs), and that people were getting connected to support and information systems. Currently, the No Wrong Door system is the first entry for constituents to find out about available services and support systems. Some options for ADRCs No Wrong Door project are the information, assistance, and counseling.

Open-Forum Discussion

Workgroup Members, Data Analysis Team, Full Committee

Commissioner Bishop noted that a course in using tools for person-centered training was recently developed. He mentioned the fact that CMS, through the HCBS rule, acknowledged person-centered planning from the DD community standpoint. Commissioner Bishop added that SDM is a place where this can be culminated and where all the stakeholders can work together to build a solution. Dr. Reynolds stated that this can also be about leading individuals into the direction of employment first, community first, and allowing them to plan for their day-to-day realities.

Ms. Swenson expressed belief that there is a moral risk with person-centered planning where parents, families, siblings, schools, and service providers are being told that the world revolves around one person. “Whenever someone says this phrase—nothing about me without me—there is a response saying: Yes and just remember, not everything is about you.” Ms. Swenson added, this means that a mother also needs to be able to keep her job, a father deserves to take a vacation, a family needs to sleep overnight, etc. In one word, the person-centered planning may be the wormhole between the family and the formal system.

Further Suggestions and Development of Draft Recommendations for 2016 Report to the President

Workgroups Sessions

Full Committee Discussions

The PCPID Workgroups reconvened and hold a 30-minute discussion session for each of the focus area of the 2016 RTP.

Meeting Adjournment

PCPID Chair

Chairwoman Petty made the motion to adjourn. Mr. Strautmanis and Ms. Weintraub 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. Complete the meeting “Evaluation Survey” by **Thursday, March 10, 2016**. (Completed)

PCPID Staff

1. Convert the meeting recordings into minutes by **Friday, April 1, 2016**. (Completed)
2. Continue convening the Workgroup discussion sessions and solicit input and feedback from all PCPID members by **Friday, April 1, 2016**. (Completed)
3. Schedule the next meeting of the Committee by **Friday, April 1, 2016**. (Completed)