



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

Committee Meeting  
November 8-9, 2018

~Minutes~

***Citizen Members***

Chris G. Neeley, Chair  
Vijaya Lakshmi Appareddy  
Olegario D. Cantos  
Emily Colson

Claudia B. Horn  
Stephanie Hubach  
Annette Liike  
Karen Moderow

***Ex Officio Members and Representatives***

Clarette H. Yen  
Representing the Honorable Jeff Sessions,  
Attorney General, U.S. Department of Justice

Carol Dobak  
Representing the Honorable Betsy DeVos  
Secretary, U.S. Department of Education

Jennifer Sheehy and Andy Ariasand  
Representing the Honorable Alexander  
Acosta, Secretary, U.S. Department of Labor

Monique Dismuke  
Representing the Honorable Wilbur Ross,  
U.S. Department of Commerce

Leola Brooks and Elisa Walker  
Representing Acting Commissioner Nancy A.  
Berryhill, US Social Security Administration

Brian S. Parsons, Representing the Honorable  
Kirstjen Nielson, Department of Homeland  
Security

Martin Pursley  
Representing the Honorable Ryan K. Zinke,  
Secretary of the US Department of Interior

***The Administration on Disabilities (AOD) - PCPID Staff***

Julie Hocker, Designated Federal Official, PCPID

Allison Cruz, Director Office of Innovation, Administration for Community Living

Sheila Whittaker, Management Analyst, Office of Innovation, Administration for Community Living

Jennifer Johnson, Deputy Director, Administration on Intellectual and Developmental Disabilities, Administration for Community Living

***Guest Speakers in Attendance***

Lance Robertson, Administrator, Administration for Community Living

Mary Lazare, Principal Deputy, Administration for Community Living

Charles McEnerney, Director, Executive and Scientific Resources Division, US Department of Health and Human Services (HHS)

Dr. David Michael Mank, University of Indiana, on Barriers and Opportunities to the Employment Landscape

Dr. John Butterworth, University of Massachusetts, on Trends in the Employment of Individuals with Intellectual Disabilities

Debra Hart, University of Massachusetts, on Post-Secondary Education as a Path to Employment

Trent Morse, White House Liaison, HHS

Sara Frattone, Attorney, HHS

Sandy Jordan, Director of Employment Programs

Jenny Spaeth, Special Assistant for Boards and Commissions, HHS

Steve Hagy, Director, Office of Budget and Finance, ACL,

Kenny Moss, Program Analyst, Office of Budget and Finance, ACL

Anastasia Lowery, Program Analyst, Office of Budget and Finance, ACL

## **The PCPID Meeting Proceedings**

### ***Welcome, Greetings, Introductions, and Statement of Occasion***

Mary Lazare

Principal Deputy Administrator for the Administration for Community Living

Ms. Lazare welcomed participants to the fall 2018 meeting and called the meeting to order, then handed the meeting over to the chair for the PCPID, Christopher Glenn Neeley, Chair and the Executive Director of the Meyer Center for Special Children.

### ***Introductions***

Christopher Glenn Neeley

Chair

Chairman Neeley welcomed participants, thanked the members present, and explained his own professional and personal interests and inspiration for participating on the Committee. The rest of the Committee introduced themselves, the entities which they represented, as well as their own profession and personal interests in the activities of the Committees, most of which included knowing or being related to someone with an intellectual disability.

Charles McEnerney swore in new members and a group photograph was taken of those present.

### ***Remarks from the Health and Human Services (HHS) White House Liaison***

Trent Morse

White House Liaison, HHS

Ms. Lazare introduces Mr. Trent Morse, White House Liaison to Health and Human Services. Mr. Morse details the role of HHS in determining public policy and opening discussions for those with disabilities. He requested direction on who the Committee would like to hear from and who should be involved in the activities and decisions of the Committee in order to accurately represent the variety of viewpoints regarding intellectual disabilities. He introduces Julie Hocker, who is the Commissioner of the Administration on Disabilities.

Mr. Morse describes his role as White House Liaison and reminds those on the Committee that all of their activities are criticized so it is important that they behave morally and ethically, even outside of the office. He moved on to explaining the priority of creating employment opportunities. He asks for feedback and ideas on improvement during the meeting.

At this point, Ms. Colson suggests including someone with intellectual disability in these discussions and active in the committee. This was seconded by Ms. Hubach. Mr. Morse requests names of individuals for consideration.

### ***Ethics Training***

Sara Frattone  
Attorney, HHS

Ex-Officio members and public are dismissed from the meeting for 40 minutes during which there is no record of proceedings.

### ***Explanation of Administration for Community Living (ACL)***

Lance Robertson  
Administrator, ACL

Mr. Robertson explains the mission and purpose of the ACL, primarily finding means of including people with disabilities and older adults into society. More information can be located on the agency website, [acl.gov](http://acl.gov). He emphasizes the importance of the Five Pillars essential to the functioning of the ACL, primarily related to employment. He encourages the Committee to reach out to Dr. Michael Marge (phonetic), who was not present but is spearheading a currently unpublicized effort to increase employment and further the Five Pillars of the ACL. Mr. Robertson closes his remarks by emphasizing that the resources and information of the ACL are open to the Committee.

### ***Federal Advisory Committee Act (FACA)***

Jennifer Spaeth  
Special Assistant for Boards and Commissions, HHS

Ms. Spaeth explains that FACA “governs any board, commission, council, conference, panel, etc. that is established by the law, the President, or an Executive Branch agency to obtain advice and recommendations.” FACA requires input from “people from the outside” and transparency in above-mentioned entities’ activities so that the public can see that they still have influence and that government leaders are not making arbitrary decisions.

Ms. Spaeth reviews the history and purpose of FACA as an effort to maintain practices that promote the best interests of the groups for which the Committee exists and for the public. She re-emphasizes Mr. Morse’s point that the Committee members’ behaviors and actions are constantly watched and criticized. FACA helps hold individuals accountable for their actions and words. She reminds the Committee that their role is only that of an advisor, not a decision-making entity. Violating FACA could influence the credibility of the Committee and therefore make the Committee’s recommendations have less weight. She explains the specific roles of Ms. Hocker and Mr. Neeley.

### ***Travel Procedures***

Steve Hagy, Anastasia Lowery, and Kenny Moss  
Office of Budget and Finance, ACL

Ms. Lazare updates the meeting agenda by moving the travel discussion forward.

Mr. Hagy explains that he wants to make sure the Committee members can focus on the purposes of the meetings, not on any issues regarding traveling to the meeting. He introduces Ms. Lowery and Mr. Moss as the primary sources of information for questions and Ms. Whittaker as the primary contact for Committee members. He explains the structure and internal functioning of his office. Ms. Whittaker will help make the travel arrangements. Each Committee member receives \$76 per diem but \$57 for the first and last days of the meeting. You do not need food receipts but the Office does require receipts for any other necessary purchases made during official duty, such as hotel, ground transportation, etc. He left the Committee with Ms. Whittaker's direct line, (202) 795-7359. Please send everything to Ms. Whittaker in a timely manner and all together. Mr. Moss offered his direct line for questions as well, (202) 795-7274.

### ***Overview of PCPID Alignment within HHS, Administration on Disabilities***

Mary Lazare

Principal Deputy, ACL

ACL was founded in 2012 and is composed of both the Administration on Disabilities and the Administration of Aging. In 2015, the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) which is a combination of experts from different backgrounds. The mission of the ACL is "to enhance the health, well-being, and independence of older adults and people with disabilities and their families and care-givers." The agency has the purpose of being involved and inclusive but also to encourage and motivate.

The ACL aims to help those with disabilities to make supported decisions. It also provides grants to states, tribes, non-profit organizations, educational institutions, universities, and other organizations with the same goals as the ACL. Ms. Lazare re-emphasizes the role of the ACL in advising the President and Congress in making decisions regarding people with disabilities.

### ***Call to Order***

Mary Lazare

Principal Deputy, ACL

Ms. Lazare called the meeting to order and announced that the order of speakers would be altered in order to wait for Ms. Cruz to arrive.

### ***Welcoming Remarks, Meeting Overview, and Approval of Agenda***

Christopher Glenn Neeley

Chair

Mr. Neeley emphasizes the importance of the different points of view and diversity of backgrounds of Committee members. He gives a special thanks to Ms. Whittaker, Ms. Lazare, Mr. Robertson, Ms. Spaeth, and Ms. Hocker.

Mr. Neeley introduces Ms. Johnson to the Committee. Ms. Lazare introduces Mr. Andrew Morris, Mr. Rohmteem Muktari, and Ms. Leslie Kaplan all staff of ACL also attending the meeting and providing assistance.

Mr. Neeley brings up the main agenda of the Committee in helping people with disabilities to find gainful employment in the growing economy. He wants to see a change in the idea of people with disabilities being limited in their abilities to work, and their skills. The Committee will examine and discuss the report and employment beginning with the employment landscape, barriers and opportunities, trends in the employment of people with intellectual disabilities, and post-secondary education as a path to employment. November 9<sup>th</sup> will be for further discussion and beginning plan development.

### ***Discussion of 2019 Report: Employment***

Mary Lazare

Principal Deputy, ACL

The Fiscal year began October first. The annual report on employment is key this year because of the low unemployment rates and more companies are practicing, or wanting to practice, inclusion for those with disabilities but they need guidance and advice on how to do so.

### ***PCPID Report to the President Procedures Manual***

Allison Cruz

Director, Office of Innovation, ACL

Ms. Cruz outlines the manual that Committee members received via email and in their attendance packets. She reiterates the strictly advisory role of the Committee.

### ***Employment Topic 1: The Employment Landscape: Barriers and Opportunities***

David Michael Mank, Ph.D.

Professor Emeritus at Indiana University

Mr. Neeley introduces Dr. Mank who has participated in researching and writing about the education and employment of people with disabilities. Dr. Mank explains that finding a decent job is a priority among those with disabilities. Society has changed its perspective to one in which the general populace has realized that people with intellectual disabilities can contribute in the workforce, to the point that many organizations are trying to find ways to hire people in this demographic. Dr. Mank's goal is "competitive, integrated employment, which means full or part time at minimum wage or higher, with wages and benefits similar to those without disabilities performing the same work and fully integrated with co-workers without disabilities."

Organizations developed to help people with disabilities to find employment need to provide support and resources for clients to compete in employment. Investment into these programs has been led by community advocates and states, not the federal government. More federal money is

invested in maintaining segregating people with disabilities than including them. Helping a large number of people with disabilities is a challenge in that each individual has their own needs and abilities. It takes a lot of time and resources to help each person. Inter-agency work is essential in this which includes the vocational rehabilitation and intellectual and developmental disabilities agencies in each state. Accomplishing these goals requires a revamp of these agencies and a change in society's perspective of providing a safe place for people with disabilities to go during the day to creating an inclusion-based society with gainful employment for people with disabilities.

### ***Employment Topic 2: Trends in the Employment of Individuals with Intellectual Disabilities***

John Butterworth, Ph.D.

Director of Employment Systems Change and Evaluation, et al.

Dr. Butterworth had three main points to discuss. First was a project on employment outcomes and services funded by the Administration on Intellectual and Developmental Disabilities. This would include a database that tracks the work of the Committee and its outcomes. Second, Dr. Butterworth wants to develop skills and technology that better enables communities to support those with disabilities who are seeking work. Lastly, Dr. Butterworth sees a need for changes in state agency policy and strategy.

Currently, only about 20% of people with disabilities who received employment support from the states are in integrated employment; 12% in competitive integrated jobs; and 6% in group supported jobs. In the past ten years, there has been about 12% growth in the number of people working in the integrated employment areas.

There are many challenges that inhibit growth such as funding, facilities, and the market. Data charts and graphs are broken down with different criteria to demonstrate the issues related to different demographics within the population of people with disabilities.

### ***Employment Topic 3: Post-Secondary Education as a Path to Employment***

Debra Hart, Ed.M.

Director of Education and Transition, Institute for Community Inclusion

Dr. Hart opens by emphasizing the importance of funding for the AIDD and ACL. The Department of Education began working with AIDD in order to provide training and assistance to the supporting individuals and groups on adapting post-secondary education for people with disabilities. This developed into "Think College" on thinkcollege.net. The website provides resources and directories for programs that help people with disabilities in post-secondary education. Think College provides training to help educational institutions transition to become more accommodating for people with disabilities. Dr. Hart discusses examples in which the Think College models have been applied and the successes of the programs as well as the struggles faced when implementing the models.

***Employment Topic 4: Employment Panel – Perspectives from Experiences Individuals with Lived Experiences***

Liz Weintraub

Senior Advocacy Specialist

Association of University Centers on Disabilities

Ricardo Thornton

Vice Chairperson

Washington, D.C. Developmental Disabilities Council

Ms. Weintraub described her experiences as someone with a disability in the workforce. She is a self-made lobbyist for others with disabilities. She expounds on the fulfillment she finds in having what she considers a real and meaningful job. She talks about her own feelings of pride and value in doing what she wanted to do and demonstrating that having a disability does not have to limit a person. One of Ms. Weintraub's primary concerns is in the lack of understanding of people with disabilities and, in particular, an unawareness of the individual masked by the disability. She seems to say that a disability should not determine the job a person has. A person should be defined by their role through their job, not by their disability.

Mr. Thornton discussed his own experiences being institutionalized. He talked about the overmedicating and death of his sister which inspired him to become an advocate for those with disabilities. He wanted to seek accountability for those in charge of the institutions and justice for those abused in said institutions. He described the injustices he felt at his various jobs and in his goal to marry his now wife, Donna. In these stories, he talks about the prejudices that people had against him and his wife, even those who were tasked with trying to help them acclimate and integrate into everyday society like social workers. He talks about how he and his wife overcame these obstacles to become advocates for themselves and others with disabilities.

***Employment Topic 5: Panel – Perspectives from the Field***

Chip Woods

Executive Director

Saint Peter's Adult Learning Center

Sandy Jordan

Director of Employment Programs

Able, South Carolina

Mr. Woods believes that "work is good." He has experience in for-profit and non-profit agencies that help people with disabilities find employment. He believes that when people with disabilities have employment, they feel value and agency in their lives. Unfortunately a lack of skills and money allows the easy dismissal of people seeking jobs. He emphasizes the need for real-life experience based education for everyone, including those with disabilities, not just academics. This is his goal at St. Peter's. They bridge the gap in communication between what businesses want in their employees and the skills taught to potential employees. Policy changes need to



occur to bring the employment of people with disabilities up from 19-20%. Society must recognize those within the discussed group as individuals and people and that they can contribute to society too. Statistics are important in determining results. Having numbers-driven incentives will help change policy and increase employment of people with disabilities. Work must be gainful and people must be properly trained for the jobs.

Ms. Jordan works in an organization that has 80% employment of people with disabilities. Fifty percent of the board are people with disabilities. It is the only organization led by people with disabilities working with a grant from ACL. They have created a peer-to-peer business model called Disability:IN. This is in order to have businesses help other businesses in the acceptance of hiring and actual hiring of people with disabilities. It causes employers to re-examine actual modern job requirements in order to open the positions to a broader population base. The Committee should be looking at both how to develop new practices and ideas and what is already available and how it can be adapted.

### ***PCPID Discussion of Report***

Christopher Glenn Neeley  
Chair

Chairman Neeley opens the floor for discussion of topics to put in the report to the President. They are as follows: shifting from shelter workshops to community-based experience; employment of people with disabilities in high school so that they maintain employment after high school; negotiating leverage deals to open door to “glass ceiling” businesses; better marketing to promote acceptance and employment of people with disabilities.

### ***Announcements to the Committee***

The Committee would like the recommendations of different agencies, as well as best practices, models, and opportunities. There will be a conference call December 5<sup>th</sup> at 10 a.m. The public can also make their own recommendations and express concerns to Ms. Whittaker. The Committee is also looking for candidates who are individuals with intellectual disabilities. Please send those recommendations to Ms. Whittaker.

The report is due by June 1<sup>st</sup>. There will be another Committee meeting in March. An email will be sent out after this meeting with a calendar of events. The Committee should start thinking about a consultant who can write the report to include the recommendations, justifications, and data to support. Committee members will be receiving the previous Committee’s report in email.

### ***Adjournment***

Chairman Neeley ended the meeting by quoting Senator Robert Kennedy, “Some people see things as they are and say why. And I dream things that never were and ask why not.” He

thanked everyone in attendance and wished them safe travels, reminding them of the conference call on December 5<sup>th</sup> at 10 a.m.