

**PRESIDENT'S COMMITTEE FOR PEOPLE WITH  
INTELLECTUAL DISABILITIES**

**Quarterly Meeting**

Thursday, September 14-15, 2006  
Hubert H. Humphrey Building  
200 Independence Avenue, S.W. Room 800  
Washington, D.C.

PARTICIPANTS:

Erica Alston	William J. Edwards	Thomas Joseph Reilly
Milton Aponte	Eileen Elias	Steven C. Rhatigan
Sally Atwater	Margaret Giannini	Laverdia Taylor Roach
Ricardo Barraza, Jr.	Jerry Gidner	Neil Romano
Herbert Bartlett	Carmela Vargas Gonzales	Kodie Sue Ruzicka
John Benison	Susan Goodman	MaryMargaret Sharp-Pucci
Valerie Billmire	Claudia Gordon	Linda Hampton Starnes
Stephen V. Bird	Harris N. Hollin	Janna Starr
James M. Boles	Stephen Hollingshead	Steve Surovec
George Bouthilet	Wade F. Horn	Dallas "Rob" Sweezy, Chair
Jewel Bazilio-Bellegarde	Kathryn Knapp	William E. Tienken
Stephanie Preshong Brown	Patricia Mantoan	Scott Weinberg
Christopher Button	Mary Kay Mauren	Sheila Whittaker
Olegario D. Cantos	Patricia Morrissey	Donna Wiesner
Jennifer Croft	Renee Pietrangelo	Deborah Wise
Sharman Word Dennis	Casey Patrick O'Halloran	Michael H. Wolf

Sally Atwater, Executive Director of the President's Committee for People with Intellectual Disabilities (PCPID or Committee) opened the quarterly meeting of the Committee by introducing herself, welcoming members, and introducing Federal staff. She provided an overview of the meeting agenda, focusing on major items including: structural and functional matters that are essential for Committee members know, such as the Federal Advisory committee Act (FACA); ethics for special government employees (including members of an advisory Committee); and the e-pay system. She noted that following those discussions, ex officio members of the Committee would make presentations describing existing programs in their respective Federal

Departments and Independent Agencies. Ms. Atwater noted that a panel of officials representing constituent organizations in the field of intellectual disabilities would make presentations. She stated that during the latter part of the day, the members would discuss potential priorities for the Committee. Following the discussion, members would make decisions on major priorities to pursue during the next couple of years. Ms. Atwater emphasized that these priorities would serve as the basis for preparing the Committee's annual Report to the President for the coming years, starting in 2007.

Ms. Atwater introduced the PCPID Chair, Dallas "Rob" Sweezy, who made a brief presentation on his past and current activities, and then asked each citizen member to briefly introduce themselves. After self-introductions by citizen members, Ms. Atwater introduced and called upon the first presenter at the meeting. A presentation was made by an attorney member from Patricia Mantoan, Senior Attorney, General Law Division, Office of the General Counsel, U.S. Department of Health and Human Services. She spoke on the Federal Advisory Committee Act (FACA). The presentation was followed by a question and answer period.

The presentation on FACA was followed by a presentation made by Michael H. Wolf of the Ethics Division, Office of the General Counsel, U.S. Department of Health and Human Services. He spoke on Ethics for Special Government Employees. The presentation was followed by a question and answer period.

Ms. Atwater reconvened the meeting after lunch and asked that Mr. Sweezy introduce the Assistant Secretary for Children and Families of the U.S. Department of Health and

Human Services, the Honorable Wade F. Horn. Dr. Horn read the Oath of Office to the new Presidential appointees to the PCPID, swearing them into office as full members of the Committee. Scrolls were presented to the new members, each of whom was given a photo opportunity with Dr. Horn.

Ms. Atwater introduced the next presenter, Deborah Wise, a human resource specialist and team leader with the Rockville Human Resource Center, Administration for Children and Families, Department of Health and Human Services. The presentation was made on the e-pay process to acquaint new citizen members with the procedures by which they would be compensated for their work on the Committee. The presentation was followed by a question and answer period.

Ms. Atwater explained the clearance process within the Administration for a Report to the President. She also spoke briefly on the Executive Order and the President's New Freedom Initiative. She highlighted its list of goals and their importance to the PCPID, in comparison to the existing goals in the Executive Order of 1996, and suggested that the Committee follow the goals described in the New Freedom Initiative since they represent the goals for people with disabilities of the current Administration.

Ms. Atwater called upon the ex officio members to introduce themselves and make summary presentations on programs in their Federal Departments or Independent Agencies pertaining to people with intellectual disabilities. Briefings were made by each ex officio representative to the PCPID, except the representative from the Department of Justice, who was unable to participate in the meeting. The presenters included:

- Secretary of Health and Human Services  
Represented By:  
Eileen Elias, M.Ed.  
Deputy Director  
Office on Disability  
U.S. Department of Health and Human Services
- Secretary of the Interior  
Represented By:  
Jerry Gidner  
Deputy Bureau Director  
Bureau of Indian Affairs  
U.S. Department of the Interior
- Secretary of Commerce  
Represented By:  
Kathryn Knapp  
Office of the Secretary  
U.S. Department of Commerce  
Co-Presenter:  
Jennifer Croft  
Disability Policy Advisor  
Office of Civil Rights  
Department of Commerce
- Commissioner of the Social Security Administration  
Represented By:  
Susan Goodman  
Consultant, Deputy  
Commissioner  
Social Security Administration
- Secretary of Labor  
Represented By:  
Christopher Button, Ph.D.  
Supervising Policy Advisor  
Office of Disability  
Employment Policy  
U.S. Department of Labor
- Attorney General  
Represented by:  
Mark Gross  
Deputy Chief, Appellate  
Section, Civil Rights Division  
U.S. Department of Justice
- Chair of the National Council on Disability  
Represented by:  
Milton Aponte, Esq.  
Council Member  
National Council on Disability
- Chair of the Equal Employment Opportunity Commission  
Represented by:  
Mary Kay Mauren  
Senior Attorney/ Advisor  
Equal Employment  
Opportunity Commission
- Secretary of Transportation  
Represented by:  
John Benison  
Departmental Office of Civil  
Rights  
US Department of  
Transportation
- Secretary of Homeland Security  
Represented by:  
Claudia Gordon  
Senior Policy Advisor  
Officer for Civil Rights and  
Civil Liberties  
Department of Homeland  
Security
- Secretary of Housing and Urban Development  
Represented by:  
Stephen Hollingshead  
Senior Advisor to the Secretary  
U.S. Department of Housing  
and Urban Development
- Secretary of Education  
Represented by:  
Donna Wiesner  
Special Assistant  
Office of Special Education and  
Rehabilitation Services  
U.S. Department of Education

Mr. Sweezy offered closing remarks, noting a very productive day; after which the first day of the two day meeting was adjourned by the Executive Director.

Mr. Sweezy reconvened the meeting at the beginning of the second day, and introduced the next presenter to the Committee, Ollie Cantos, Associate Director for Domestic

Policy at the White House, who serves as the special point person relating to concerns pertaining to people with disabilities at the White House. Mr. Cantos spoke on the New Freedom Initiative.

Mr. Sweezy then invited members to identify their priority issues for the coming years and discussion of those suggestions followed.

### **Vouchers**

The Committee discussed the suggested priority issues of school vouchers for families who wish to place their special needs children in the schools with the best programs. It was noted that when moving into a new school district it is extremely difficult to procure the necessary services for a child with disabilities. Some members countered with the concern that vouchers would only seclude children with disabilities in a “boutique” school setting. The belief was then expressed that parents know what is best for their children and any program that puts money in their hands to get the necessary education and services for their child will result in improved quality of life.

### **Public Awareness**

The Committee discussed the importance of public awareness - which included a discussion of awareness for many groups of people: parents, self-advocates, health care professionals and the general public. The idea was proposed of a series of PSA's to bring to the forefront disability issues. The justice system was also discussed in relation to public awareness and the lack of awareness/knowledge on the part of law enforcement professionals, probation officers and judges. The Committee also discussed the use of the schools and full inclusion programs to broaden public awareness. It was noted that when children go to school and learn along side children with disabilities,

they are less likely to have a fear of working with them in the future, such as in the job market. Parental rights were also discussed as an issue relating to public awareness and the need for a portal of information to inform parents of their rights and the rights of their child. Lack of awareness among health care workers was also discussed and it was mentioned that there is currently a curriculum in use developed by the Association of Obstetrics and Gynecology that has been very successful in educating health care professionals about the needs of people with intellectual disabilities. It was also noted that the curriculum was tied to CME's giving an incentive to practicing physicians to complete the program. It was also noted that most of the other topics discussed contained some aspect of public awareness, such as assistive technology.

#### **Inequitable Application of Laws**

Members discussed the inequitable application of laws across the country, particularly education laws such as IDEA. The idea of producing a "best practices" report, or a report on Dept. of Education's Blue Ribbon Schools was suggested. It was also suggested that such a report include the added value that people with intellectual disabilities bring to a school.

#### **Clinical Application of Research**

The Committee discussed the importance of bridging the gap between research and clinical application. More awareness is needed of scientific breakthroughs across a variety of disciplines (most notably, neuroscience and assistive technology) that could potentially improve the lives of people with intellectual disabilities. One idea for a potential report was to highlight the research that was currently being done with potential application to people with intellectual disabilities. It was also suggested that experts in the field be invited to address the Committee on these issues. It was also

noted that a list of disability programs was available at

[www.gao.gov/publicationfederaldisabilityassistanceJune2005](http://www.gao.gov/publicationfederaldisabilityassistanceJune2005).

### **Job Skills and Training/Support**

The Committee discussed the issue of job skills and employment ready people. Some Committee members expressed the concern that businesses looking to hire people with disabilities were only looking for the “least disabled” person they could find.

Committee members expressed the need for increased training and support for people who were able to work. There was also discussion, as noted previously, of the connection between employment and a greater value placed on people with intellectual disabilities. The Committee noted that by making people with intellectual disabilities monetarily valuable in the employment market, the rest of the community would follow. There was also discussion of the difference between training and support from a self advocate perspective.

### **Assistive Technology**

The Committee discussed the wealth of new technology and assistive devices in development and on the market, and the disconnect between development and use in the disability community. It was noted that assistive technology is key in leveling the playing field for people with intellectual disabilities. This issue was also discussed from a public awareness perspective and it was noted that discussing assistive devices, public awareness and employment together is key.

### **Medicare/Medicaid**

The Committee discussed the history of the Medicare system and noted that it was not designed to address the issues of lifetime special needs. The Chair noted a program within Medicaid that allows money to follow the individual from institutional care to

community based care. Another member expressed the desire to see the benefits system federalized in the hopes that it would allow greater access and information to parents, and provide a greater opportunity for self direction of services and supports.

### **ADA and Religious Access**

The Committee discussed the various ways in which the ADA has improved access for people with disabilities, but that the faith community has not risen to the same level of access. It was noted that in the case of places of worship there is the least amount of legislation regarding access. It was noted that every piece of research indicates that people with intellectual and physical disabilities have as much religious faith as the rest of the population, but that they are not afforded the same access.

### **Possible Directions of the Committee**

In addition to the topics discussed above, several other suggestions were made regarding the potential direction of the Committee. The hope was expressed that the Committee would take a leadership role and address a topic that had not been previously addressed by the Committee. It was also suggested that the Committee not limit itself to one topic, but address a “laundry list” of the important issues facing people with intellectual disabilities across the lifespan. Another suggestion was to look at past Committee reports and evaluate what had been done with regards to those suggestions. It was noted, however, that it could be difficult to ascertain what had been done, particularly given that much of it may not have been done by the Federal government, but by organizations and businesses.

Following presentations on priorities by members, the Chair called for general discussions, noting that three main focus areas that may serve as a base for



subcommittees: research applications (Chair, Harris Hollin); education/equitable application (Chair, Linda Hampton Starnes); and public awareness (Chair, Neil Romano). The Chair acknowledged the need for ancillary or ad hoc groups for certain areas as identified by individual members, including: school vouchers, employment, criminal justice, housing, and aging pertaining to people with intellectual disabilities. These areas may be explored independently along with the three main focus groups.

Further discussions included: request for identification and distribution of web sites of presenters and ex officio members; offering of a web site identifying all programs serving people with disabilities; identification of an agency as a resource for research; and the idea of “trolling for dollars” for the Committee.

February was selected as the best month for the next in-person meeting. Some members expressed a preference for the latter part of February. The Chair noted February 11 as a possible date to consider.

The Chair officially closed the meeting at 3:02 pm.