



Minutes
President's Committee for People with Intellectual disabilities
Quarterly Committee Meeting
January 29-30, 2004

Attendees:

PCPID Civilian Members:

Vijaya L. Appareddy, M.D.
Nancy C. Blanchard
James T. Brett
Mary C. Bruene
Arlene Clancy
(Representing Bishop William E. Lori)
Claudia L. Coleman
Brenda A. Leath
Kenneth E. Lohff
Edward R. Mambruno
Alvaro A. Marin
Kim Porter-Hoppe
Michael J. Rogers
Rev. Lon R. Solomon
Windy Smith
Karen L. Staley
Gene C. Stallings
Annette M. Talis
Madeleine C. Will

PCPID Ex-Officio Members:

Milton Aponte (NCD)
Representing Lex Friedman
John P. Benison (DoT)
Representing Norman Y. Mineta
ReJane "Johnnie" Burton (DoI)
Representing Gale A. Norton
Nique Fajors, (DoC)
Representing Donald L. Evans
Margaret Giannini, M.D., F.A.A.P. (HHS)
Representing Tommy G. Thompson
Claudia Gordon (DHS)
Representing Tom Ridge
Troy Justensen and
Joan Mele-McCarthy (ED)
Representing Roderick R. Paige
Mary K. Mauren (EEOC)
Representing Cari Dominguez
Julian Manelli and Glenn Sklar (SSA)
Representing Jo Anne Barnhart
Marcia Martin (HUD)
Representing Alphonso Jackson
Nancy Skaggs (DoL)
Representing Elaine L. Chao
Daniel W. Sutherland (DHS)
Representing Tom Ridge
Michele Tennery (CNCS)
Representing David Eisner

Guest Speakers:

Bill Anderson
Director
Office of Medical Policy
Social Security Administration

Gary Siperstein, Director
Center for Social Development in Education
University of Massachusetts Boston

Neil Romano
The Romano Group

Stephanie Lee, Director
Office of Special Education
U.S. Department of Education

Wade F. Horn, Ph.D.
Assistant Secretary
Administration for Children and Families
Department of Health and Human Services

Michael Morris
Director
National Disability Institute
National Cooperative Bank

Rick Rader, M.D.
Director
Exceptional Parent Magazine
Special Liaison for Family Health Care Concerns

PCPID Staff:

Sally Atwater
Executive Director

George Bouthilet, Ph.D.
Research Director

Laverdia Roach
Special Assistant to the Executive Director

Jarnice Roach
Administrative Assistant

Lena Stone
Program Specialist

Sheila Whittaker
Budget Officer

Guests

Bruce Appelgren (AAMR)
Susanne Armstrong (NDSS)
Doreen Croser (AAMR)
Doug Domenech (White House Liaison)
Steve Eidelman (The Arc)
David Eigor (DoE)
Karen Flippo (NADD)
Lisa Fox (PCPID) [Personal Assistant to Michael Rogers]
Mario Garrido [Personal Assistant to Ed Mambruno]
Susan Goodman (NDSS)
Andrea Lack (NDSS)
George Jesien (AUCD)
Faith McCormick (ADD)
Anna Middlebrook (EEOC)
Renee Miskell (Heritage Reporting)
Mildred Rivera (EEOC)
Jaime Robman (TASH)
Rickie Sabia (NDSS)
David Sprenger (National Fragile X)
Kari Smith (Guest of Windy Smith)
Michael Smith (Guest of Windy Smith)
Janice Starr (The Arc and UCP Public Policy Collaboration)
Sue Swenson (The SRC)
Nancy Weiss (TASH)
Kasey Wendell (The Arc)
Rouita Wisienksi (Autism Society)

Thursday, January 29, 2004

The President's Committee for People with Intellectual Disabilities (PCPID) convened at 9:30 a.m. on Thursday, January 29, 2004, in Washington, DC. The purpose of the meeting was to continue dialogue and consider recommendations regarding preparation of the 2004 Annual Report that will be submitted to the President.

Opening Remarks

Chairperson Madeleine C. Will welcomed PCPID members, speakers and guests. She asked that members review the minutes of the October 16-17, 2003 quarterly meeting. Mr. Brett made a motion for approval of the minutes. The motion was seconded and the minutes were approved as written.

Mrs. Will welcomed new ex officio representatives, John Benison, U.S. Department of Transportation, and Marcia Martin, U.S. Department of Housing and Urban Development. She stated that this meeting is truly significant because the Committee will focus on taking the annual report to another level of improvement. In addition, Assistant Secretary for the Administration for Children and Families, Dr. Wade Horn, will have a dialogue with Committee. Due to scheduling conflicts, Dr. Horn will join the Committee today at 4:00 p.m. for 30 minutes rather than as originally scheduled for tomorrow (Friday).

Mrs. Will relayed that Deputy Commissioner Martin Gerry of the Social Security Administration (SSA) had asked that the Committee discuss the Social Security determination requirements at this meeting. Bill Anderson, Director of the Office of Medical Policy, will provide more information before the Committee gets to the stage of actually planning its next workshop with SSA.

Social Security Administration Disability Determination Requirements

Ms. Will introduced Mr. Anderson, Director, Office of Medical Policy, Social Security Administration.

Before making his presentation, Mr. Anderson introduced Sue Roecker, Associate Commissioner and Glenn Sklar, Acting Deputy Commissioner, in the SSA Office of Disability Programs. Any questions that the members have should be directed to Mr. Sklar, Mr. Anderson or Sue Roecker.

Mr. Anderson made a presentation on the SSA mental disorders listings criteria, related issues and the National Research Council report on intellectual disabilities (mental retardation). Members should contact Mr. Anderson at bill.anderson@ssa.gov if they want a copy.

Mr. Aponte asked for clarification on the statement Mr. Anderson made regarding reasonable accommodations from employers under the Americans with Disabilities Act (ADA).

Mr. Anderson provided an example of an employee who has an impairment that interferes with his ability to work. In order to satisfy the ADA, the employer must provide reasonable

accommodations to that employee in order for him to do his job. The SSA does not look for reasonable accommodations. If an individual can't do the job as he/she did it prior to a disability, SSA says that they are unable to do that job and they will be eligible for benefits.

Mr. Rogers asked if the SSA could examine ways to make it easier for people with disabilities to say that they can do things. Mr. Anderson responded that administering a disability program with ADA in it will have some very, very big challenges in it.

Introduction of Daniel Sutherland

Chairperson Will introduced Daniel Sutherland, the Officer for Civil Rights and Civil Liberties (OCRCL), U.S. Department of Homeland Security. Mr. Sutherland provides legal and policy advice to the Secretary and senior officers of the Department on a full range of civil rights and civil liberties issues. His experience has been primarily in the areas of discrimination against immigrants and discrimination against people with disabilities.

Mr. Sutherland thanked the Committee and expressed his appreciation to the Committee for asking him to speak. He introduced his colleague, Claudia Gordon, an attorney, who recently joined his office. Ms. Gordon was formerly with the National Association of the Deaf Law Center, the National Council on Disability (NCD).

Mr. Sutherland provided a brief overview of the Department of Homeland Security (DHS), explained what they are doing and discussed their plans regarding advancing interests of people with disabilities.

Claudia Gordon expressed the Department's commitment to meet the needs of people with disabilities. Because people with disabilities have inherent knowledge about what works and what is effective for them in a disaster and emergency situation, they need to be involved. In November 2003, Secretary Ridge called a meeting with all of the national leadership organizations on disabilities. After 9/11, NCD very quickly took the lead and started planning for emergency preparedness for people with disabilities. They produced a manual which Ms. Gordon shared with the PCPID.

Ms. Gordon encouraged the audience to let her office know what their areas of concern are and how the OCRCL we can meet the needs of people with intellectual disabilities.

Mr. Mambruno asked if the OCRCL had taken any specific steps to provide persons with disabilities, especially persons with intellectual disabilities, the opportunity to seek employment with Homeland Security and, if they had, were they entry level positions across the board.

Mr. Sutherland responded that his office is trying to focus on both entry level and senior level positions. So far, they have only done a series of entry level internship programs but are getting ready to announce a contract with a headhunter firm that will specialize in identifying people with disabilities that have advanced degrees and who could fill GS-12 to the SES positions. DHS is working with other agencies and particularly with the Department of Labor in this endeavor.

Presenter PCPID Dialogue

Michael Rogers mentioned that he has a very difficult time in going through security checks at the airports. He uses a wheelchair and crutches. When he goes through security at the airport, he is asked if he can stand up. If he stands up using his crutches, then he is asked to remove his crutches. Of course, if he removes his crutches, he has to sit down, because he can't stand up without the crutches. He asked what can be done to improve the procedures.

Ms. Gordon said that the OCRCL is committed to ensuring that security measures do not interrupt civil rights and civil liberties, do not infringe on them, and do not infringe on property and privacy.

PCPID member, Milton Aponte, pointed out that people with intellectual disabilities, such as his daughter, would not be able to read the manual that Ms. Gordon bought with her.

Ms. Gordon explained that the manual is an example of the kind of efforts that are taking place. It shows that they are looking for ways to partner with federal and private partners. Once an official manual is developed, it will be a model for people with disabilities.

Ken Lohff asked if any evacuation policies and procedures exist that would give priority to people with disabilities.

Mr. Sutherland explained that there is no one evacuation procedure that Washington could mandate. Each building is different: different in size and structure; some have elevators and some don't. There is no one size fits all.

FEMA has information on its website on evacuation procedures. The OCRCL hopes to put together a national conference on this subject later in the fall of 2004 in order to get people talking through the issues and coming up with better answers to some of those issues.

Mr. Benison shared with the audience that the Department of Transportation (DoT) has developed guidelines on emergency preparedness for people with disabilities within DoT, its contractors and visitors to DoT facilities. The website address is www.drc.dot.gov. Mr. Benison asked that the PCPID provide feedback with respect to the section on people with intellectual disabilities.

Ms. Will asked if anybody at the meeting had heard about home security issues, measures and interventions, at the local level, as it relates to persons with intellectual disabilities.

Ms. Clancy, representing Bishop Lori, responded that a plan is in place in the Valley area of Connecticut. Ms. Clancy is on the Board of Directors for the Valley Association for Retarded Citizens. Many of their people work in a sheltered workshop situation. The folks that are in group homes and in apartments have also been invited, and they all have small ID badges which they can grab as they have to leave a situation. They have been told where to go in the event of

an emergency situation.

Sally Atwater suggested the possibility of holding a special summit on emergency preparedness for people with intellectual disabilities at a large church or some other establishment with a large attendance (such as the McLean Bible Church which had a disability summit last year).

Karen Staley informed Mr. Sutherland that The Arc has been heavily involved in putting together a manual for the police department on how to interview people and how to search for people in various communities. The training packets that Claudia Gordon referred to could be modified with TSA screeners.

Mr. Sutherland provided contact information for Ms. Gordon and himself: claudia.gordon@dhs.gov or daniel.sutherland@dhs.gov. He said that DHS will participate with the Committee over the months to come.

Mrs. Will thanked Mr. Sutherland and Ms. Gordon for their presentation. She asked Mr. Aponte to provide the members with information on the NCD Workforce Conference that would take place in February.

Mr. Aponte conveyed that a group of parent advocates has organized a conference on employment for people with disabilities on February 8, 9, and 10 in Broward County, Florida. He produced a brochure that provided details about the conference, speakers and the program.

Neil Romano was been invited to join the NCD conference to help strategize how to develop the approach and strategy for this conference. Mr. Aponte extended an invitation to all of the members to attend the conference. Governor Jeb Bush and the Commissioner of the Social Security Administration will be address the conference, as well as many other key leaders.

Mrs. Will next introduced Martin Dannenfelser, Jr., Deputy Assistant Secretary for Policy and External Affairs, Department of Health and Human Services.

Mr. Dannenfelser thanked the Committee members for the important work they have put into the Committee and said that the President and others in his Administration appreciate the sacrifices they have made to serve on the Committee.

A discussion took place by telephone conference with Michael Morris and Committee members. Mr. Morris thanked Mrs. Will, the Committee Chairs and staff for their help in providing information, explanations, and documentation of points for inclusion in the report.

Mr. Michael Morris informed the members that the final product would be in two formats: a booklet and a CD. The CD will include President Bush's radio address when he signed the amendment to the Executive Order that changed the name of the Committee, and some interviews and audiovisual material that will help make the case for the recommendations of each subcommittee. Both the report and the CD are meant to be tools for providing recommendations to the President, built on the platform of the New Freedom Initiative.

Mrs. Will reiterated the Committee's thanks and gratitude for Mr. Morris' hard work, skills, talents and judgment. The floor was then opened for discussion with Mr. Morris.

Mr. Stallings asked (1) if the Committee thought that the President will read this report and (2) if they felt it was too long.

Mr. Morris responded that an accompanying tool, such as a quick briefing paper and the CD, would probably be provided to the President, or someone at the Cabinet level, and that it would take no more than 5 to 10 minutes to review the full set of recommendations.

Mrs. Will added that Troy Justensen, when he was in the White House Office on Domestic Policy, assured her that the President is going to read this report.

Mr. Lohff asked if it would be feasible to put some sort of trailer at the end of the report that includes two to four recommendations on what the President might actually do to assist in this effort and asking him to respond to the Committee as to whether or not he felt that he can act on those requests.

Mrs. Coleman suggested that the community of persons with intellectual disabilities be defined in the beginning of the report, because with the Committee name change, people may not be sure which population we're addressing.

Dr. Appareddy asked why the report makes no reference to the aging population.

Mrs. Will replied that no recommendations with respect to people with intellectual disabilities who are aging had been made by the Committee.

Mrs. Porter-Hoppe asked when the Committee would start working on the piece that will be sent to the President of the United States.

Mrs. Will said that the draft document that was before the Committee is the piece that will be sent to the President and the next step is to finish the draft. Members will have an opportunity to suggest changes before the document goes to print.

Mrs. Porter-Hoppe reminded members that the report has to be ratified. She asked if it was the Committee's intention to submit an 8-1/2 x 11 report with a blue cover to the President, or is it their intention to send a brochure-like version, that is more like an executive summary, with some true family stories in it.

Mrs. Will informed the members that the report and brochure would be sent to them electronically for review and it can be ratified by email.

Mr. Aponte expressed concern about having two pieces that may go in different directions; if

they are complementary, you may lose some by not having them both together in a single product.

Mrs. Will responded that two pieces was the will of the Committee.

Mr. Lohff recalled that the Committee's concern was to have the report in summary form so that at least that portion would get read by the President. Everyone else should also have an opportunity to read the shortened version of it.

Mrs. Will explained that there will be a CD and executive summary included in the report. She asked the members to send their suggestions to her via email.

Mr. Mambruno recommended that, since the mission of the PCPID is to serve people with intellectual disabilities, the photo on the report should be of consumers; that we include their success stories and then lead into the recommendations. He felt that too much emphasize was being placed on the name change.

Ms. Will concurred that it was a valid point and suggested that the Committee make the decision.

Mrs. Staley proposed setting a deadline for receipt of comments from members of Tuesday, February 3, 2004, and March 15 as the deadline for the mock up version. The deadline for the final camera ready copy would be May 1, 2004. After discussion by the members, it was the consensus of the Committee to follow that timeline.

Mock Up Presentation of Annette Talis, Chair of the Subcommittee on Education

“Public schools must prepare students with intellectual disabilities for a place in the economy and the workforce of the 21st century. We know this is a priority of the President. What we as a Committee want to see happen under the No Child Left Behind Act, to develop the skills and dispositions that are relevant to employment, that the social service and educational system create a seamless, and a pre-K continuum of service for students with intellectual disabilities that supports their access to being a member of the workforce of this country.

“We believe that reading is a fundamental skill that opens doors for people and that reading needs to be a high priority for students with intellectual disabilities. In moving this population, we now have them in the schoolhouse doors, but we need them to exit with reading skills to the level that they can, and we need to make that an agenda item for the education community. Currently, Wisconsin spends a billion dollars on special education for all students with disabilities, and they have a 92 percent unemployment rate for adults with intellectual disabilities. They can do a lot better with that money.”

Mock Up Presentation of Kim Porter-Hoppe, Chair of the Subcommittee on Public Awareness

Our charge was to change the face of those with intellectual disabilities. “In May 2003, our Subcommittee was instrumental in changing the name of the Committee to the President’s Committee for People with Intellectual Disabilities. Our public awareness campaign will help to heighten the awareness of those with intellectual disabilities. Collaboration with corporate America to conduct a public awareness campaign that changes understanding, expectations and awareness of the abilities of children and adults with intellectual disabilities is paramount.

“Ms. Porter-Hoppe shared with the Committee that, as a result of the two roundtable discussions -- one on education and transition to employment and one on public awareness -- Neil Romano of the Romano Group, continued to strive for a focus on changing the face of those with intellectual disabilities. He has been working collaboratively with Wal-Mart’s private foundation. Wal-Mart has graciously offered to give Mr. Romano’s private foundation, and in collaboration with PCPID, \$250,000, to start the process for our commercials, website, and the public awareness campaign. Mrs. Porter-Hoppe extended her thanks and gratitude to Mr. Romano.”

Mock Up Presentation of Ed Mambruno, Chair of the Subcommittee on Employment

“Assistant Secretary Horn, I would like to thank you for the financial support you've given our committee in allowing us to attend and participate in the many meetings that we've had the pleasure to attend. The Employment Subcommittee has recommendations that we would like to bring to your attention.

“A blended waiver is our first priority. A blended waiver will allow persons with intellectual disabilities the opportunity to gain meaningful employment with private or public entities. Without the blended waiver, they come across obstacles such as exceeding their income limits, which will take away their health benefits.

“Our second recommendation, and probably the strongest recommendation, is a qualified savings account. This will allow persons with intellectual disabilities the opportunity to save, for parents to participate in long-term savings accounts, to put money away for training and to put money away for unexpected crises. This is an item that usually bankrupts a family. Employment, like I said is our first priority.

“We have gained much meaningful collaboration with federal agencies. The Social Security Administration assisted us in holding two roundtables last year. Just this morning, the Department of Homeland Security representative mentioned that they were actively seeking to hire persons with intellectual disabilities -- people at entry level positions, as well as high level positions. This is an ongoing process.”

Mock Up Presentation of Ms. Leath, Chair of the Subcommittee on Family Services and Supports.

“Our subcommittee's focus has been on improving the quality of life for persons with intellectual disabilities across their life span. Our approach has been to look at concrete ways to positively impact individuals and their families, both personally and collectively. This, for us, has required changing the current paradigm for family services and support.

“We focus our attention on crafting strategies that promote greater coordination, integration, collaboration and accountability at all levels of decision making and service delivery. We believe there is still room for creative uses of the HCV waiver program to support improved community integration and support services. We also believe that a forum is needed that would allow parents and families to engage in dialogue with health workers and support peer workers so that they can have their concerns heard and their issues validated in a public forum.”

Mrs. Will pointed out that the Committee had invited a group of representatives from the disability community as guests at the meeting. In the coming months, it is hoped that the Committee can have a larger meeting with more representatives from the disability organizations and get their input. She asked the guests to identify themselves.

Steve Eidelman, Executive Director, The Arc of the United States.

Patricia Swenson, the Arc of the United States.

Bruce Appleman, representing the American Association of Today.

Susan Goodman, National Downs Syndrome Congress.

Karen Bluebow, National Association of Councils on Mental Disabilities.

Anna Coparetti, EEOC.

Janice Star, The Arc and UCP Public Policy Collaboration.

Casey Michael, The Arc and UCP Public Policy Collaboration.

George Schick, the Association of University Centers on Disability.

Dave Springer, representing the National Right to Life Foundation.

Ricky Sabia, National Downs Syndrome Society (by telephone).

Andrea Lack., the National Downs Syndrome Society (by telephone)

Jaime Robman, Director of Governmental Relations for TASH (formerly the Association for People with Severe Disabilities)

Attitudes on Intellectual Disabilities during the Last Fifty Years

Dr. Siperstein's presentation focused on his findings of a review of over 500 documents that have been published since 1950 on attitudes and disabilities. Dr. Siperstein noted that major changes have taken place since 1950. A lot has been written about the paradigmatic shifts that have occurred in terms of education and employment. We've gone from a custodial model to an empowerment model. We've gone from state facilities all the way to full community inclusion.

Regular education teachers have negative expectations about students with intellectual disabilities, and they don't support inclusion.

Of two to three percent of people in the United States with intellectual disabilities, 90 percent or more are only mildly impaired. In the United States, two-thirds of the adult populations believe that children with intellectual disabilities are best served in separate schools.

Changing Negative Attitudes toward People with Intellectual Disabilities

Mr. Romano informed the audience that he is the head of The Romano Group. He has spent over 20 years doing large public and private sector health initiatives. He recently sold his company and retired. Mr. Romano noted that he has run many public service campaigns. During his career, he has learned that no public service announcement is ever going to change the attitude of a human being, but they can make people think. He became interested in the issue of disabilities across the board for personal and public reasons.

He noted that employment, education and inclusion are extremely important to the Committee. It has discussed doing a public relations campaign focusing on these areas to show that people with intellectual disabilities are competent. Mr. Romano mentioned that Coach Stallings had a conversation with Wal-Mart and Wal-Mart might be willing to assist in the public awareness campaign. A public relations program was proposed to Wal-Mart that would be tied to a website and promoted so that companies across the nation will know that people with intellectual disabilities are available to be hired; that there are places they can go to find people; and that they can be productive employees and improve their bottom line profits.

Wal-Mart liked the proposal and agreed to fund it. Mr. Romano reminded the PCPID that because it is a federal agency, it cannot, in and of itself, affect that. So, he was asked to form a separate committee to bring the people in the community together to work under one umbrella.

Presentation on a Success Story:

Mrs. Lee's discussion was about her experiences in trying to change public attitudes at the local level. She has a daughter with Down Syndrome. She discussed lessons she has learned during the last 20 years that affect public policy and changing attitudes. The biggest challenge in policy reform is changing people's hearts, minds, and attitudes. Another lesson learned is that it must involve individuals with intellectual disabilities themselves, to whatever extent, not in a way that they're being used, but in a way that they're really involved.

Mrs. Lee recommended that the public awareness effort be done in concert with people who care about our children.

Mrs. Lee noted that under the No Child Left Behind Act, there is a requirement that the test scores be disaggregated for four subgroups, including children with disabilities. And, for the first time, there is real accountability. Those groups are expected to meet what's considered

proficiency. In support of the Act, Mrs. Lee said that she has been spreading the message that these children have value.

PCPID Dialogue with the Administration for Children and Families, Assistant Secretary, Wade F. Horn, Ph.D.

Dr. Horn stated that the President feels very strongly, as he and Secretary Thompson do, that every person has dignity and worth. He noted that it doesn't mean most or almost everybody; it means everybody. If we really believe that, it means that we, as a society, have to do things differently than we're doing now. It means that we have to welcome everyone into the mainstream. We have to ensure that everyone has the maximum degree of independence possible.

Dr. Horn mentioned the belief that the ideas shared with him were very important and said that there is a lot that we need to do in terms of public education. As a person who is involved in public policy in government, he said that he is particularly intrigued with some of the Committee ideas regarding government policies and how we may inadvertently interfere with the ability of people at the individual local level in achieving that degree of independence.

Dr. Appareddy informed Dr. Horn that, because there are so many regulations, it is very confusing for parents on where to get information. She asked Dr. Horn how often the different agencies or different factions work together and, if they haven't, could he make it happen. Dr. Horn's response was that, while he believes it is really important to do so, it is very difficult to get the federal government to coordinate, not just across programs within an agency, but across the agencies themselves.

He suggested that Sally Atwater, Dr. Giannini and other Ex Officio members give him some ideas on how we can really drive that internally.

Dr. Horn offered to have a discussion with Jo Ann Barnhart, Commissioner of the SSA, and former Assistant Secretary at ACF. He asked Mrs. Blanchard to provide him, through Sally Atwater, a list of concerns and said that he would personally take them to Ms. Barnhart, sit down with her for a couple of hours, go through the list, talk it through to her, and then report back to the members.

Dr. Horn stated that he was shocked when he learned that the unemployment rate for people with disabilities is 92 percent; that it is a national shame and we can do better.

Dr. Horn mentioned that, in Washington, the two greatest virtues are patience and perseverance. If you demand change next week, it's not going to happen; if you simply give recommendations and wait, it's not going to happen either. What is required is to put forward the recommendations, continue to work on them, and push them forward.

Friday, January 30, 2004

Overview of the PCPID Mission, Accomplishments and Future Challenges.

Mrs. Will asked the Subcommittee Chairs to give a very brief summary of their Working Group discussions. Each Chair was allowed two minutes to make their report – a total of ten minutes for all five reports.

Edward Mambruno, Chair, Subcommittee on Employment: The Subcommittee had a long discussion and hashed out some problems with the report, but they want to get the report published and don't want to put any more obstacles in the way. The Subcommittee supports making the report more concise, if that is possible.

Brenda Leath, Chair, Subcommittee on Family Services and Supports: The Subcommittee has added one recommendation to its list: have persons with intellectual disabilities designated and certified as an underserved population. This recommendation is in response to attempts to try to improve access and increase supply of providers in the health care arena. Mrs. Leath suggested another recommendation that should be an over arching one incorporated into the executive summary: that the civil rights, liberties and dignities of people with intellectual disabilities, with respect to the environment and to terrorism, tactical strategies, as developed and practiced by the Department of Homeland Security, and agencies, be protected.

The Family Services Subcommittee also talked about trying to move forward with the formal document to approve it, after making some minor language changes. The Subcommittee also talked about some distribution and marketing strategies.

Annette Talis, Chair, Subcommittee on Education and Transition: The Subcommittee has been rethinking the entire section on education, to make it tighter, clearer and to use some terms and language that are they had heard in the State of the Union address, which some of the other subcommittees have also used.

The Subcommittee added a few recommendations regarding the Department of Education professional development funds, specifically for teachers that specialize with this population, and learning about the standards and assessments. We discussed how to advance this, and have already been in conversations with the National School Board Association (NSBA), about getting behind these initiatives.

Kim Porter-Hoppe, Chair, Subcommittee on Public Awareness: The Subcommittee members felt that their section of the Report was concise enough and that they could move it forward.

They also talked about marketing and dissemination of the Report, such as talking to the governors and lieutenant governors of the individual states, and sending letters and notices to introduce the annual report and what the Committee's direction is. One suggestion was to get copies of the Report to their Department of Education, Department of Employment, and

Department of Health and Human Services at the State level. It would be nice to get the annual report with an attached letter from a member of that state.

The Subcommittee briefly discussed the possibility of a partnership with the non-profits that Neil Romano is setting up, and looks forward to hearing from him on a regular basis.

Mrs. Will thanked the Subcommittee Chairs and said that all suggestions were excellent.

Chairperson's Meeting with Ex Officio Members

Mrs. Will discussed her short meeting with the ex officios who had presented a number of ideas. Nique Fajors, Department of Commerce, talked about adding some language layered in around volunteerism. John Benison, Department of Transportation, suggested expanding some of the language around transportation. Mrs. Will asked Messrs. Fajors and Benison to discuss their recommendations with the members.

Mr. Fajors expressed belief that the structure of the Report should be changed a little, *e.g.*, to bring the recommendations for each focus area up to the front and make it a concise, 10 or 12 recommendation summary, which would be a more powerful presentation.

John Benison said that the U.S. Department of Transportation (DOT) sees transportation as pivotal to employment for individuals with disabilities. If there is an opportunity to put some language on how transportation can benefit individuals with intellectual disabilities in gaining employment or enhancing access to employment, he will look at ways to incorporate that in the Report that might be helpful. He looks forward to working closely with the Employment Subcommittee, as his career has been focused on that area and he is an expert at finding employment for individuals with disabilities in the federal government.

After a lengthy discussion by Committee members, a motion was made and seconded to have the Report ready to go to the printers in one month.

Gene Stallings emphasized that several members' terms expire on May 11, 2004, and that the Committee has spent too much time on the Report not to get it done for submission to the White House prior to that time.

George Bouthilet, Ph.D., stated that the document needs to be approved as soon as possible by the current members and that no additional names could be added to it afterwards. It also has to go through clearance, to get it approved to go to print.

Milton Aponte made a motion that, based upon the Homeland Security issue, the Committee recommends the creation of a subcommittee to deal with issues that have to do with Homeland Security. All of us are aware of the importance of the Office of Homeland Security, the largest of all federal departments, with 117,000 employees. Everyone is aware of how it is affecting

people as we travel and particularly people with the development or intellectual disabilities.

The motion was seconded and approved.

He also said that the report needs to be edited for business speed. Neil Romano, several others and even our ex-officio members continue to impress upon us the need for brevity and boldness to what we have in this report. The highlights ought to be bulleted so that as a businessperson, our President can have and probably will have a staff briefing so that they can go through it really quickly. Then the final thing is that the Report needs to conclude with a positive message.

Milton Aponte expressed belief that the language of the Report covers this area, in terms of the philosophy of the President, in terms of the philosophy of the Committee, and in terms of the recommendation of the value of work that the people with disabilities are doing in the work environment.

Brenda Leath asked if the report would be translated into Spanish. Mr. Mambruno said that it can be done easily using Babelfish on the Internet, which translates it automatically.

Annette Talis brought up the sense of patriotism that Michael Rogers had brought to the table. A brief discussion took place by the members on the fact that people with disabilities are Americans and they wanted that introduced earlier in the recommendations.

Mrs. Will said that in the event that some of the members are not here in May, she wanted to express how much she has enjoyed working with the Committee members. It has been enormously difficult work. Members were appointed late and they were sort of behind the curve from the outset, in terms of time. They had to build relationships and build trust.

The Committee has done something very important in terms of the content of the recommendations. It's very important how the Report looks, but the words between the covers are much more important. She expressed her feeling that the Committee had come up with a set of recommendations which, if implemented by the Administration, would constitute a transformation of the system of care for persons with disabilities. We've said that the premises upon which the system is based are wrong. That the system is built on the assumption that people can't be productive and need to be dependent. That's different from the rhetoric. The rhetoric is about personal and economic freedom and what we are saying is to align the rhetoric with the actual policies so that the real outcome in economic and personal independence and freedom can be achieved.

The Committee has a very coherent scheme which, if implemented, starting with going to OMB and having them look across the programs to ensure that the right outcomes are being achieved and measuring those, looking at things like wages earned and how many people are renting or owning their own place.

We've talked about the issue of control of resources. We've talked about the issue of administrative support to help families and individuals with disabilities to deal with the

complexity of the regulations and the forms. Imagine in the world of the 21st century a civil servant who calls you on the phone and says, "You need this form. I will get it for you. I will help you fill it out and get it to the appropriate agency." That's the kind of administrative support we need. That actually happened to me last week. We are making progress.

We've talked about the importance of education programs, developing the right skills, knowledge, dispositions and post-secondary programs. Creating greater opportunity for persons with intellectual disabilities to develop skills, careers, and communicate to employers the things that they've learned.

We've talked about a strategy for working across the federal programs, a strategy of blended waivers and reinforcement for agencies to pool their resources to collaborate and to integrate that collaboration into the mainstream of services.

We've talked about public awareness and the importance of changing public attitudes. We can change all sorts of statutes and regulations, but if the average American continues to believe that persons with intellectual disabilities are not competent, should maybe not be in regular school, maybe can't work, maybe not in our communities, we are not going to see the changes that we want.

We're not going to see our folks with intellectual disabilities dreaming the dreams that we want them to dream.

If we communicate all of this in a very succinct, clear way, it will have an impact throughout the land. It may not be that we're on the front page of the newspaper the day after the publication, but it's something that people will read. It's very thoughtful, coherent and it reflects on us and our work very well. I hope that you all feel proud of your participation in this committee.

I say goodbye. Godspeed and I hope to see you again soon. Thank you.

At 12:06 p.m., the meeting was adjourned.