



Minutes
President's Committee for People with Intellectual disabilities
Quarterly Committee Meeting
October 16-17, 2003

Attendees:

PCMR Members:

Vijaya L. Appareddy, M.D.
Nancy C. Blanchard
James T. Brett
Mary C. Bruene
Olivia R. Colvin
Zoraida Fonalledas
Brenda Leath
Edward R. Mambruno
Kenneth E. Lohff
Alvaro Marin
Kim M. Porter-Hoppe
Karen L. Staley
Lon Solomon
Gene C. Stallings
Annette M. Talis
Madeleine C. Will
Claudia Gordon
Representing Bishop Lori

PCPID Ex-Officio Members:

Milton Aponte (NCD)
Representing Lex Friedman
ReJane "Johnnie" Burton (DoL)
Representing Gale A. Norton
Nique Fajors, (DoC)
Representing Donald L. Evans
Martin H. Gerry (SSA)
Representing Jo Anne B. Barnhart
Margaret Giannini, M.D., F.A.A.P. (HHS)
Representing Tommy G. Thompson
Mark Gross (DoJ)
Representing John Ashcroft
Mary K. Mauren (EEOC)
Representing Carrie Dominguez
Robert Pasternack, Ph.D. ((ED)
Representing Roderick R. Paige
William O. Russell (HUD)
Representing Mel R. Martinez
Daniel W. Sutherland (DHD)
Representing Tom Ridge
Michele Tennery (CNCS)
Representing James Manning

PCPID Staff:

Sally Atwater
George Bouthilet, Ph.D.
Jarnice Roach
Laverdia Roach
Lena Stone
Sheila Whittaker

Members Not in Attendance:

Kathy Hargett
Bishop William E.Lori

Agenda Participants

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

Wade F. Horn, Ph.D.
Assistant Secretary
Administration for Children and Families

Michael Morris
Director, National Disability Institute
National Cooperative Bank

Dr. Rich Rader
Exceptional Parent Magazine
Neal Romano
The Romano Group

Gary Siperstein, Director
Center for Social Development in Education

Subcommittee Resource Persons:

Dr. Rick Rader
Exceptional Parent Magazine

Guests:

Kim Martiny,
Stephanie L. Smith, (OSEP)

THURSDAY, OCTOBER 16, 2003

The President's Committee for People with Intellectual disabilities (PCPID) convened at 9:00 A.M. on Thursday, October 16, 2003, in Washington, DC. The purpose of the meeting was to continue dialogue regarding preparations of the 2004 PCPID Annual Report to the President.

Opening Remarks

Chairperson Madeleine C. Will welcomed PCPID members and guests. Mrs. Will announced that the President had issued an amended Executive Order on July 25, 2003 in which he approved changing the name of the "President's Committee on Mental Retardation" to the "President's Committee for People with Intellectual Disabilities." President Bush also appointed four new Ex-officio members to the Committee: Honorable Donald L. Evans, Secretary, Department of Commerce, Honorable Norman Y. Mineta, Secretary of the Department of Transportation, Honorable Gale Norton, Secretary of the Department of Interior and Honorable Tom Ridge, Secretary of the Department of Homeland Security. Representatives of the departments were Nique Fajors, (DoC) Rejane "Johnnie" Burton (DoL), and Daniel W. Sutherland (DHS). The Department of Transportation had not yet designated a representative.

The minutes of the May 12-13, 2003 Quarterly meeting of the Committee were reviewed. A motion was made and seconded to approve the minutes as written.

Introduction of Christopher Kuczynski, Director for Domestic Policy, Domestic Policy Council, The White House

Mrs. Will introduced Christopher Kuczynski. Mr. Kuczynski is responsible for coordinating federal government activities in support of the New Freedom Initiative, President George W. Bush's comprehensive plan for the full integration of people with disabilities into all aspects of American life. He is a nationally recognized speaker on the American Disabilities Act and the rights of individuals with disabilities.

Mr. Kuczynski invited the Committee members to contact him on issues involving the New Freedom Initiative at the White House, as he will continue to play an active roll in implementing the Initiative.

He stated that we needed to focus on employment integration in the work place, education, training, transportation supports, healthcare supports, and making sure that

our benefits programs (Social Security Programs) are not a disincentive to work toward full integration.

Presenter/PCPID Dialogue

Milton Aponte asked how Florida could resolve the issue of high school graduates with special diplomas who cannot get a job in the public sector because, they are told, that they don't have an adequate high school diploma. He asked for suggestions on the best approach to take: the county, the city or ADA?

Mr. Kuczynski responded that the ADA would be the best approach, possibly as a matter of employment discrimination. Title I of ADA states that an individual with a disability is qualified for a position if that person meets the job related requirements and can perform the jobs' essential functions, with or without reasonable accommodations. If a person can demonstrate that he or she is able to perform the essential functions of the job, even though the person may have a different kind of diploma or special diploma, that person may be able to argue that he is qualified for the position

Karen Staley inquired about an October 15, 2003, *Washington Post* article about President's Bush's commitment to down size government. Part of the down sizing is to out source some federal jobs, some of which have the potential of eliminating employment for many people with disabilities. Ms. Staley and the Committee felt that there should be some type of domestic policy or something exempting the person with the disability from losing their position due to out sourcing.

Mr. Kuczynski stated that he had had discussions at OMB regarding the rules and the Circular A76 question. On a preliminary basis, OMB said that:

- The OMB circular does not require that any particular jobs be out sourced or competed for out sourcing.
- Agencies have quite a bit of discretion in terms of identifying what jobs they compete and, after a competition has been announced, whether they continue that competition.
- Agencies can consider factors in terms of exercising that discretion -- any number of factors, including the economic impact of the competitive out sourcing and perhaps the impact that it would have on individuals with disabilities who would be out of those jobs if the jobs went outside the government.

There is no rule that certain jobs be automatically competed. There is agency discretion on which jobs will be competed and there are factors that agencies are supposed to be taking into consideration.

The number of people who have actually lost positions in the government as a result of the competitive sourcing has been rare. Mr. Kuczynski invited Committee Members to view the OMB website for more information on this issue.

Dr. Giannini asked Mr. Kuczynski if he plans to have an agenda to address this issue at the White House and if it is his role is to push that envelope for a group such as this one.

Mr. Kuczynski said that his role is to hear what this community and other communities have to say to move issues forward. Talking with agencies and getting their ideas on items that need to move forward will help in putting together that agenda.

Mrs. Will thanked Mr. Kuczynski for coming to the meeting.

Acknowledgment of Commissioner Patricia Morrissey

Mrs. Will expressed the Committee's gratitude to Patricia Morrissey, Commissioner of the Administration on Developmental Disabilities, who provided logistical supports and services for today's meeting.

Briefing on the Olmstead Decision

Robinsue Frohboese, Principal Deputy Director, Office for Civil Rights, U.S. Department of Health & Human Services.

Mrs. Will introduced the next speaker. Dr. Robinsue Frohboese has more than 25 years experience in disability rights and civil rights policy and enforcement. The Office on Civil Rights (OCR) is responsible for advising the HHS Secretary on civil rights issues impacting the Department's activities, ensuring compliance with federal civil rights laws in HHS programs, and the new privacy regulation under the Health Insurance Portability and Accountability Act. As the Principal Deputy Director, Dr. Frohboese is the senior career official in OCR with responsibility for overseeing program operations and policy development in headquarters and the ten OCR regions.

It took the Americans with Disabilities Act of 1990 to create a federal right to services in the words of the ADA Regulation in State Government entities. That included what has become known as the Integration Regulation, and it requires State and Local Government entities to administer services, programs and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.

This regulation was interpreted by the Supreme Court in a case that has now become very famous, *Olmstead v. L.C.*, in 1999. For the first time, the Supreme Court created a national federal right for all individuals with disabilities to live in the most integrated setting. With that right, the court found that unnecessary institutional segregation is, in fact, a form of discrimination based upon disability and that it was prohibited by the

ADA. The Department of Justice, in writing the regulations, properly interpreted the ADA to create this right to community integration.

In the *Olmstead Decision* certain criteria were established to set forth the frame work for individuals with disabilities to exercise this right. It depended upon three factors,

- 1) Treating professionals determine that services in the most integrated settings are appropriate for the individual with the disability
- 2) The affected person, the qualified person with the disability, does not oppose services in the most integrated setting
- 3) That services in the most integrated setting can be reasonably accommodated by the State or Local Agency providing the services, taking into account the resources available to the State and the needs of others with disabilities.

Looking at whether services can be reasonably accommodated, the Supreme Court said it would look at a couple of things that the State was doing:

- 1) Whether the State had developed a comprehensive effectively working plan to develop community services and the whole community structure system as an alternative to institutional services. These plans are now known as the Olmsted Plans.
- 2) Whether the States were making reasonable modifications,
- 3) Whether it would make fundamental alterations to provide these services and whether it was creating a waiting list that was moving at a reasonable pace.

Committee Member Michael Rogers asked for clarification of the definition of “reasonable pace” in the Supreme Courts eyes.

Dr. Frohboese explained that in the *Olmstead Decision*, a lot of questions need to be answered on a case-by-case basis. There is no specific definition on what is a “reasonable time.” Interestingly enough, there is a whole other area of the law interpreting Title 19: Medicaid funded services that talk about prompt and reasonable services. That area of the law is probably moving faster than interpreting the ADA and its Integration Regulation, and coming up with some frame work of how quickly individuals with disabilities need to be provided services. That’s more in the context of people who are waiting for entry to a Medicaid funded institutional service as apposed to community services.

The *Olmstead Decision* has shaped federal activities. Just weeks after he took his oath of office in February of 2001, President Bush unveiled his New Freedom Initiative, an initiative in which he has committed to all Americans with disabilities to fulfill the promises of the legislation that his father signed some ten years earlier in the Americans with Disabilities Act. The New Freedom Initiative has many different parts but one of the overriding themes is that it really is a broad based initiative to remove barriers to community living persons with disabilities. It focuses on all of the critical elements that this Committee was so instrumental in keeping at the top of public consciousness and, federal policy development of providing opportunities for each individual with a

disability to learn, develop skills, engage in productive work, choose where to live, and participate in community life.

A key part of the New Freedom Initiative was that the President called for swift implementation of the *Olmstead Decision* and committed to issuing an Executive Order. Executive Order 13217 was issued in June 2001. It talked about how the President wanted the federal government to ensure full implementation of the ADA and swift implementation of the *Olmstead Decision*.

In the Executive Order, the President picks up the language used by the Supreme Court in the *Olmstead Decision* that unjustified isolation or segregation of qualified individuals with disabilities through institutionalization is a form of disability based discrimination prohibited by the ADA. The President called upon the federal government to work with and help States to swiftly implement the *Olmstead Decision*. In the Executive Order, the president directed six agencies, the Department of Health & Human Services, Department of Education, Department of Labor, Department of HUD, and the Social Security Administration, to take a long hard look at policies, practices, statutes, and regulations to determine if they needed to be revised to improve the availability of Community Services for Individuals with disabilities.

As this effort progressed, the Department of Transportation, The Veterans Administration, and the Office of Personnel Management joined in the effort. The President asked Secretary Thompson to head up this effort. In looking at agency policy and programs, the President recognized how important it was to have the views and the input of stake holders, consumers, family members and providers.

The Department of Health & Human Services, based upon the agencies' self review, as well as the many listening sessions that were conducted, developed a report that Secretary Thompson provided to the President in March 2002 called *Delivering on the Promise*. Over 400 specific solutions and action steps were recommended that the federal agencies to take to promote community living. A copy of the report is available to the Committee on request.

Since the *Olmstead Decision*, the Office of Civil Rights has received nearly 600 hundred complaints. OCR has been very successful in resolving these complaints on an informal basis without having to resort to methods of enforcements of either withholding federal funds or referring them to Justice for enforcement. OCR has also been working with the Department of Justice to develop alternative dispute resolution techniques to mediate and resolve *Olmstead* complaints. They are very active in collaborating with other HHS components and are very involved in working with States providing technical assistance in developing the *Olmstead* plan. OCR now works with over forty States and just about every State is now in some phase of developing an *Olmstead* Plan. The National Conference of State Legislators has done an exhaustive review. In addition, in August of 2003, the National Council of Disabilities published a very comprehensive 300 page summary on a State-by-State basis of all of the *Olmstead* activities.

Presenter/PCPID Dialogue:

Questions were raised on the status of the \$1.7 billion and whether states would have to complete for grants. Dr. Frohboese conveyed that the money is still in the budget but we are currently operating under a continuing resolution. We're very hopeful that all of the New Freedom Initiative money will be in the final budget when it is approved. Currently everyone's focus is on the Medicare Prescription Drug Package.

Regarding eligibility for funds, a lot of the details still need to be worked out for exactly for what this program would look like but it is a broad based concept and all States would be eligible to receive funding.

Maggie Nygren, CMS, clarified that the \$1.75 billion is a demonstration project that States will compete for.

Dr. Frohboese said that Secretary Thompson wants to get the word out that funding that is available for community services and for agencies within the Department to work together in collaboration. For example, the Administration on Aging is working very closely with the Centers for Medicare and Medicaid.

Mr. Stallings asked how states would apply for these funds. Dr. Frohboese referred him and the Committee to the CMS web-site, www.cms.hhs.gov, which provides specifics on how to apply for the funds and how to use money. It is federal money that goes to the States to assist with State funding in developing programs. The money is available through the Medicaid Program, through Community Based Waiver Programs, and through Grants and Demonstration Model Projects that are being funded by the Department.

Milton Aponte asked if any agencies have been set up to oversee implementation of *Delivering on the Promise*. Dr. Frohboese replied that this is one of the functions that Chris Kuczynski will be taking over as Central Coordinator of all the federal agencies. Although HHS has been leading the effort, Dr. Giannini has been very active in convening the other federal agencies and following through on the status of their commitment.

In response to a question on protections for people who leave institutions and go to the community to have equal or better care, Dr. Frohboese said that that is the purpose of Money following the Individual which will put the choices in their (the individual's) hands.

Briefing on CMS Real Choice Systems Change Grants, Discussion of Individual Control of Budgets

Dr. Margaret Nygren, Technical Advisor to the Disabled and Elderly Health Programs Group in the Center for Medicaid and State Operations within the Centers for Medicare and Medicaid Services (CMS).

Mrs. Will introduced Dr. Margaret Nygren. Dr. Nygren provides leadership and technical assistance in program policy areas that support the President's New Freedom Initiative. She has most recently worked to develop "Money Follows the Individual" legislation and to create new opportunities for States to develop new Respite, Quality Assurance, and Aging and Disability Resource Center programs for people with disabilities and the elderly. Prior to working with CMS, Dr. Nygren served in the fields of developmental disabilities and aging in a variety of capacities, including program administrator, researcher, policy analyst, and consultant.

Dr. Nygren discussed the CMS Real Choice Change Grants and Individual Control of Budgets. States or territories are eligible to apply for any of the grants, except for the Technical Assistance Grants and Family to Family Health Care and Information grants. The Family to Family Healthcare and Information Grants are open to organizations that were governed by individuals who have a disability or a long term illness. States and other entities were notified of the grant opportunity through publication in the Federal Register, a solicitation on the web-site, and a press release. For future reference, all grant opportunities are available on the CMS web-site at www.cms.hhs.gov.

Ten different grants were described:

1. The "Quality Assurance and Quality Improvement in the Community Based Services Grants" that are designed to help States improve their QA/QI Programming. These grants were only awarded to States. They are essentially infrastructure grants to improve their ability to better support their home and community based waivers, to ensure that their data collecting and oversight of home and community base services are appropriate, and to improve their methods for actively including consumers and family members in the quality assurance and improvement systems. Nineteen grants were awarded in this category.
2. The "Money Follows the Person" initiative grant (sometimes called "Money Follows the Person" or "Money Follows the Individual." The Money Follows the Person Initiative Grants were only open to States and its purpose is to help States develop strategies to reform their financing and service designs for long term supports. These particular grants are given in order for States to do the behind the scenes work, provide a coherent package of home and community based services and State plan services, but allows money to follow the person from one situation to another. It will also allow them to change their financing systems so that individuals can transition from institutions to community based settings. Nine grants were awarded in this category.
3. The Independence Plus Initiative Grant opportunities are only open to States to help States create applications for independence plus waivers or demonstration projects.

Independence Plus Projects are the only mechanisms that allow individuals to have cash budgets that they can self direct. By offering this grant opportunity, we were hoping that States would be able to craft good Independent Plus programs that would have individualized budgets. Twelve grants were awarded in this category.

4. The Community Integrated Personal Assistance Services and Supports grants, known as CPASS, were only open to States to assist them in improving their personal assistant services. By improve, we specifically mean ensure that they are consumer directed and have maximum individual control. Eight grants were awarded in this category.
5. Technical Assistance Grants, a mechanism by which CMS provides technical assistance to all of its grantees. Rutgers's University was the grantee this year.
6. The Family to Family Healthcare Information and Education Centers Grants category was open only to consumer controlled organizations. They went to individual groups, not States. The purpose of these grants is to support the development of family information and education centers for children with special health needs. They provide education and training to families and develop and disseminate information on home and community based services. We hope that they will be able to collaborate with other Family to Family Healthcare Information Centers and promote the philosophy of individual family directed support. Nine grants were awarded in this category.
7. Community Based Treatment Alternatives for Children grants, also known as the CAC, was available only to States to help them develop comprehensive community based mental health service programs, and improve their service delivery system for children with serious emotional disturbances, who would otherwise need services in an in-patient psychiatric facility. Six grants were awarded in this category.
8. Respite for Children. The purpose of this grant was to help States conduct a study to assess the feasibility of providing respite to caregivers of children as a Medicaid service. Such projects are expected to build elements that are responsive to individual needs, and offer the opportunity for self direction. Six grants were awarded in this category.
9. Technical Assistance for Consumer Task Forces grant. Many of our projects require that there be an advisory board or a consumer task force populated by individuals with disabilities or their family members. We awarded a Technical Assistance grant to assist those task forces and advisory committees to be the most influential and effective as they can be in program oversight and evaluation. One grant was awarded in that category.
10. Under the Real Choice Systems Change Grants was Respite for Adults. The grants were awarded to States for the purpose of conducting a study to assess the feasibility

of providing respite to caregivers of adults as a Medicaid Service. Four Grants were awarded in this category.

Presenter/PCPID Dialogue

Milton Aponte asked if a non profit corporation that the State designates as the lead agency for that particular grant application would qualify.

Dr. Nygren explained that the State Instrumentality is really a matter of State law. States, themselves, determine who their instrumentalities are. In some States, State Universities may be State Instrumentalities. These grants have been awarded and they are not eligible to apply at this time. In our next grant funding cycle for fiscal year 2004 we will be very clear on the solicitations which grant categories that non profits can apply for.

Dr. Nygren referred the Committee to the press release on direct services workforce grants at the HHS website, www.hhs.gov.

The Real Choice Change Grants have a maximum life of thirty six months (3 years). Some proposals were to expand all the grant funds in less time, to do a one or two year project, but they have up to 36 months to complete them. After 36 months, the grants funds are specifically designed to assist the States in developing their independent plus waiver or demonstration projects. Once they receive their waiver or demonstration that goes on and on and on. The funds are behind the scenes infrastructure development and application writing money, planning, implementation, infrastructure development and that sort of thing - all the behind the scenes work that has to be done before the funds actually reach the person. Within three years you should see the actual services being provided.

Mrs. Will asked if extensive evaluation and data collection is being done to determine cost effectiveness and quality of service.

Dr. Nygren responded that there is a requirement to do so. In order to provide the grants, you have to report back to Congress to indicate that the grant money was spent effectively and you do have to evaluate it in an on-going fashion.

Briefing on the Family Opportunity Act

Robert ("Bobby") Hillert, Congressional Staff, Office of Congressman Pete Sessions, U.S. Congress, Washington, DC.

Mrs. Will introduced Robert Hillert. Mr. Hillert is Legislative Assistant for Congressman Pete Sessions, from Texas. A native of Dallas and the 32nd District in Texas, he has served as a legislative assistant to Congressman Sessions (TX-32) since May of 2001. Bobby's legislative duties include Healthcare, Telecommunications, Information Technology, Education, and the House Results Caucus – a caucus that focuses on promoting initiatives that will lead to a more efficient, high-performance government.

When Congressman Sessions came to Congress in 1996, he began hearing stories from families who are not as fortunate as he was. In 2000 Congressman Sessions received a letter from a grandmother from Masque Texas named Tara Nelson, telling him about her grandson, Dillon Lee James.

In 2000 Congressman Sessions introduced legislation called the “Dillon Lee James Family Opportunity Act.” Medicaid takes care of a lot of children. But there are families who go beyond the poverty level and are no longer eligible for Medicaid. A lot of these children's families can't afford the health insurance to take care of them. Sometimes the children have to go to institutions. Some families have to quit their jobs and they can't take job promotions or receive raises.

Mr. Hillert provided an overview of the Family Opportunity Act. It created a Medicaid buy-in for children whose disabilities are defined by the Social Security Act - up to 250% of the poverty level. This Act also allows children with severe mental disorders, who currently require institutional care, to be eligible for home and community based waiver services.

Another significant aspect of the Act is that it provides waivers or health insurance for these families in all 50 states and DC. A family of five reaches the poverty level at \$21,540. Obviously, that is a very low number, but if they go above that, they lose their Medicaid Health Insurance for your children. If they go up to 250 %, that would make quite a difference for these families. At least 300,000 children will be eligible for this.

Ted Kennedy is the sponsor in the Senate and Pete Sessions is the Sponsor in the House.

Presenter/PCPID Dialogue

A discussion ensued on how the Committee can help move this bill forward. The Committee, as a whole, cannot lobby, but members as individuals can. Mr. Hillert suggested that individuals talk to the house leadership and let them know how important it is.

The bill is in the Energy and Commerce Committee in the House, because they handle Medicaid. The Senate worked with it and got it out of their Committee. They had a mark-up on it. They have to try to get it to the Senate floor for a vote. In the House, it's a matter of leadership taking it out and getting it to the working committee.

Mr. Aponte mentioned that there is a provision in the federal law through the Medicaid program that allows a person under twenty one to receive the services without considering the income of the family.

Mr. Hillert suggested working on incorporating that into the Family Opportunity Act which would perhaps push this legislation along faster – modeled after a right to work.

In response to a question regarding dual eligibility, Mr. Hillert said that a person eligible for the Family Opportunity Act would not be considered “dual eligible.” The bill focuses on children under the age of 18.

The Administration has not taken a position on the Act. The bill currently has 70 co-sponsors at the end of the 107th Congress.

Mark Gross asked if the \$7.5 billion appropriation was cause for resistance in moving the bill forward. Mr. Hillert replied that, “yes,” it’s expanding the entitlement.

Mrs. Will mentioned one of the key things we have been looking at is a way of reducing fragmentation. It’s not just about jurisdictions; it’s about helping and making it possible for people to do two things: (1) control their own resources so they can put together what they need to be working within the community, and (2) having the help of those programs that lend those resources. She asked Mr. Hillert if there is an understanding in Congress that this isn’t happening out there.

Mr. Hillert said that this legislation is really a wake-p call for a lot of members of Congress; it has introduced the issue to a lot of people. Many members of Congress are very interested in this issue now, and they never thought about it before Congressman Sessions started talking about this issue. It’s an issue that all members of Congress and their staffers need to be lobbying for and be educated more on it.

The speaker of the House, Mr. Hastert, and his staff has grown very interested in this legislation. Majority Leader Tom Delay and Mr. Hastert are two are very good contacts.

Mr. Aponte asked if the bill would require the State to make a matching contribution. Mr. Hillert said that the States will have the option to do that. The federal government will provide most of the funds it and will do most of the work. States have worked with the Governors on this issue, and they fully embrace it.

A Committee member pointed out that the States are in crisis over their Medicaid funding and this bill isn’t coming at the right time. It’s a great bill, but each State is looking at how to cut back the Medicaid Services.

That \$7.5 billion represents what the federal government can give; it doesn’t necessarily represent 100% of the cost of this service. In normal Medicaid Services, it’s a split. It depends if the State wants to offer its full 45%.

Mr. Solomon asked how this bill differs from the MR Waiver. Mr. Hillert replied that the biggest point is that it ensures that every eligible child is covered. He wasn't sure how it differs from the MR Waiver.

Mr. Solomon emphasized the importance of the MR waiver to the Committee. If the Congressman has a sincere desire to fix the problem, that's great. But the bill isn't any better than the MR Waiver, unless the federal government imposes these services regardless of State Legislators.

Mrs. Porter-Hoppe discussed a program in the State of Michigan called the Children Special Healthcare Services Program that Medicaid pays for. Families of children that are above the poverty wage of children with severe disabilities, as well as healthcare issues, are covered.

On returning home from another quarterly meeting, she learned that the State of Michigan has now changed the way people qualify for Medicaid. They can work, have savings accounts, and actually do different things.

Michael Morris explained to Mr. Hillert that the Committee represents the President and the Committee does not have the authority to go over the President and get his support on this bill.

Framework of the Annual Report to President George Bush

Michael Morris, Director, National Disability Institute, National Cooperative Bank Development Corporation

Ms. Will informed the Committee that traditionally the Committee has contracted for someone to write the report. This year, the Committee has asked Michael Morris, Director, National Disability Institute, to do so.

Michael Morris is the Director of the National Disability Institute (NDI) of the National Cooperative Bank Development Corporation (NCBDC) in Washington, D.C. He has over 20 years of experience in systems change activities to advance employment and entrepreneurial opportunities for individuals with intellectual disabilities with the collaboration of government, the business community, and private Foundations.

Mr. Morris made a presentation on the framework of the report. He distributed two handouts to the Committee members: "The Disability Maze" and "New Freedom Conceptual Frame Work."

He shared with the members the most common challenge: the myriad of systems, supports, programs, agencies, and funding streams that consumers are expected to decipher. He called this fragmentation the "Disability Maze." In fact, it's multiple systems literally pulsating in front of you and behind you; multiple decisions to be made

simultaneously concurrently some times, other times sequentially, and sometimes in contradiction with each other.

Item III of the New Freedom Conceptual Frame Work. shows certain key facets of the President's activities, particularly in his move towards making more sense of government, making government make sense of the lives of American citizens with and without disabilities. Certainly, for this President, it is a special recognition of the sensitivity on how to find and navigate that path to his "New Freedom."

The starting point of the frame work has to relate to thinking about

- a) A more effective and efficient government.
- b) Whether a recommendation made by the Committee is going to provide a path that expands opportunities for economic and personal freedom for all Americans, including Americans with intellectual disabilities.
- c) A new way of measurement about the way government operates in concert with State and local governments and with private sector investment blending of resources that can work together in a collaborative way to achieve preferred individual outcomes.

In reviewing minutes from previous subcommittee meetings, three kinds of barriers that are affecting people with intellectual disabilities have stood out:

1) Attitudes: Changing public attitudes and the attitudes of school children - their attitudes towards their peer groups, children with intellectual disabilities, the attitude of the employer in the work place, and their attitudes towards hiring, retaining and advancing individuals with intellectual disabilities.

2) The 40 to 60 different federal programs and agencies that have a piece of the strategy that might advance personal and economic freedom for individuals with intellectual disabilities. The second type of barrier is clearly structural: the complexity, the over-regulation, and the fragmentation of programs and supports.

3) Public policy. We're not all pushing the boat in the same direction, and at the same time we have public policy. Social Security says that you need to prove that you are unable to work in order to continue to receive government benefits. At the same time, three other initiatives in commerce, in small business, and the Department of Labor are trying to figure out how we make sure that people work. Just one of many examples of policy conflicts that some of the recommendations are going to relate to on how we deal with the attitudinal barriers.

First, we have to replace low expectations and misunderstandings with new higher expectations of capability and capacity for individuals with intellectual disabilities to contribute as valued members of their communities, regardless of age or circumstance. Second, change the structure of the complexity over-regulation and fragmentation of

programs and supports, and encourage the blending of resources across funding streams to achieve preferred individual outcomes. Third, what is going to support those changes that are, in some cases, recommendations about change in government policy.

There are three different types of groupings. Whether you are working in the group on Technology, Family Support Issues or Employment issues, these three types of barriers exist. Effective recommendations that deal with attitude, structure, and policy can be grouped together. Then, one has to go a step further.

In reviewing some of previous minutes of discussions, the Committee has tried to determine what would it look like, what would be that system of support is if we did overcome the attitude barriers, the structural barriers, and the policy barriers?

- Make it simpler to understand.
- Make it seamless regardless of the funding stream or the agency responsible for administering that funding stream.
- A new type of measurement that gets at how we can overcome these types of barriers.

Three measures have been identified and the Committee is seeking three ultimate outcomes: (1) Increase consumer control of public resources. (2) Get away from the fragmentation of these different systems, agencies and funding streams. (3) Encourage savings and assets development.

There are 26 different recommendations here; some are policy recommendations, some removing attitudinal barriers and some are about breaking down and pushing forward the blending of resources to achieve these kinds of objective.

Think about how much anyone can absorb, whether it's the President and his top advisors or people with intellectual disabilities. Think about what some of the important priorities within your Subcommittee. Are some more important than others; are some more important because of one of these three measures? Think about holding government accountable in new ways. Every federal agency and the Office of Management and Budget is going through a set of performance measures twice a year and the programs are getting the grades. Those grades are affecting their future budget recommendations, how they structure their programs, the way they think about their current policies, and whether there is a need for change.

What they have not done is put on new lens which is a set of measurements around impact related to individuals with intellectual disabilities, an impact in terms of these three parts in the measurement system.

1) Increase consumer controls and direction of resources, the notion of individual budgets.

2) The blending of resources. For example, in what way did the Departments of Labor and Education work together in the past year? In what way did the Administration on Developmental Disabilities work with the Office of Community Services, two agencies within the same agency?

3) To lead to these types of preferred objectives, in what way, in terms of recommendations, did we actually empower individuals and families to look at their approach and actually see an improvement in gaining assets? Encourage savings, gain assets and providing real choices in terms of quality of life.

Presenter/PCPID Dialogue

Ms. Leath expressed concern for her Subcommittee because they have been working on issues across the life span and human birth defect and that isn't in the recommendations. She also felt that there could be more on family support.

Michael Morris concurred with Mrs. Leath and said that it is not an exhaustive list. Additional recommendations well thought through will be added into this conceptual plan.

Mr. Mambruno asked Mr. Morris if he felt that the Committee should focus more on eliminating the splintering of programs and responsibilities for the accountability issue. Should the emphasis should be on the splintering programs or accountability?

Mr. Morris explained that the Committee has to focus on both. Different Administrations all look at re-engineering the government. They focus on moving and restructuring. It's probably the reason for measurement number one, which is, rather than get government to restructure and put the focus of responsibility back on the individual, let them have more control and decision making authority for themselves and with their support system around them.

Accountability of government is equally important but the accountability that we have is that we have been counting and measuring the wrong things. In terms of people with disabilities, for too long we were simply measuring how many people receive what services. It is only recently that we began to talk about outcomes.

Mrs. Will agreed that we have not held government accountable for the proper outcomes; that has produced fragmentation, and the first task is look at the objectives. She inquired of Committee members, what are the big objectives that you want to achieve? Mrs. Will noted that the Committee has been able to start developing that list in the disability community and has a long list. But, PCPID has not been able to implement those things.

Mark Gross felt that the first thing we should define is the desired outcomes from government services for different types of people who have different types of disabilities? The second thing is, how to get all of the various programs and funding streams coordinated toward step one. The third thing is how to determine that agencies are doing

a good job? How do you decide that if you are holding them accountable or if they're doing things right or not? If the focus is so much on what we want to accomplish here, the families and the individuals themselves have the opportunity and the authority to dictate where the funds go for their disabled child, but ultimately, down the road, you run the risk that failure is the families own fault.

Nique Fajors asked if the Committee could get access to learning why things weren't implemented or how they were handled in previous reports. He suggested that it wouldn't hurt as an input into the process.

Dr. Frohboese responded that the things we are talking about today are things that were talked about in the mid-1960s when the Committee was created. Does that mean that we have made no progress in 22 or 23 years? Or do we do one thing for this Administration and then when that Administration is gone, we have to adjust everything to fit that Administration? It seems like the people that we represent are getting the short slip every time and we are not making progress on improving their lives.

Mr. Gross felt that there has been a lot of progress in the last 40 years. The reports year after year are a part of a continuance, that's all.

Mrs. Will reminded the Members that one of the things that this Committee is doing different is developing an action plan. For example, we want to recommend a Public Awareness Campaign to the President.

Mr. Stallings recommended that the Committee suggest a plan to pyramid it down to where the caregiver would know how to get the funds to make the quality of life for these individuals the very best they can.

Mrs. Will explained that that would depend upon which state a person lived in and that the government has to take responsibility and be held accountable for it. She informed the Committee that the idea of focusing on measurement came from discussions that the Committee had at the Chair level. The PCPID wants to go to OMB and ask them to work with us. The PCPID is also working on partnering with a non profit that works in this area of performance measures, and together come up with something that would be citable to the OMB.

Ken Lohff raised the issue of environments where people with disabilities are able to self care is important. We need to create supportive environments where individuals have the opportunity to fulfill their personal responsibilities. Our message to the President should be that Americans with disabilities can do a lot more for themselves if we help to create environments that allow them to flourish in fulfilling that responsibility.

Mrs. Will emphasized submitting a set of recommendations to the President around policy and systems change, but, at the same time, we want to give the family a blueprint/road map on how to do it for their own youngster. She asked the Committee to think about how to accomplish that.

Presentation on Options for Visual Presentation of Annual Report

Nancy Blanchard, Member, President's Committee for People with Intellectual Disabilities and President, Safety Signs, Inc.

Tape inaudible.

The meeting then recessed for Subcommittee Working Group sessions.

Thursday, October 17, 2003.

Mrs. Will reconvened the meeting at 9:30 a.m. on Thursday, October 17, 2003. She reported that the PCPID is required by law to have the Subcommittee Chairs report on their recommendations for the Annual Report. Claudia Coleman, Chair of the Assistive Technology (AT) Subcommittee, and Annette Talis, Chair of the Education Subcommittee will report via telephone conference.

Report of the Assistive Technology Subcommittee

Mrs. Coleman reported that the AT Subcommittee has six recommendations.

1) The AT Subcommittee recommends that the PCPID host an assistive technology forum. This forum would brainstorm federal support programs, analyze the gaps, establish a multiyear agenda, determine how to stimulate manufacturers to include the disability community in their product designs, create synergy between government programs and AT providers in developing new, innovative tools, develop collaboration efforts with the various departments within the government. That's what we are doing now with Commerce and Social Security. The AT Subcommittee suggests possibly 25 to 30 people who will represent programs within various government agencies, manufactures that provide assistive technology tools, and probably universities that are doing a lot of research and demonstrations.

2) The AT Subcommittee recommends the inclusion of a vignette of a person using assistive technology in the Annual Report. The Subcommittee would like to show how a person's quality of life or independent living is improved by using Assistive Technology.

3) The AT Subcommittee supports the creation of an AT Subcommittee as part of the ICDR. ICDR is the Interagency Committee on Disability Research that's headed up by Steven Tingus at NIDRR. There are already five Subcommittee's which include and medical rehab, the New Freedom Initiative and technology transfer. Assistive technology is certainly picked up by Technology and probably part of the New Freedom Initiative Subcommittee. The AT Subcommittee is looking for a focus of attention specifically on cognition. A lot of technology is available for mobility and physical disabilities but we need a focus on intellectual disabilities.

4) The AT Subcommittee supports the addition of assistive technology to the dual waiver recommendation (Medicaid & SSI) where consumers can control where monies may be applied so they can purchase assistive technology.

5) People with intellectual disabilities lag substantially behind all other groups in our society in the utilization of technology. The AT Subcommittee proposes a network of "Research Centers of Excellence in Technology and Intellectual Disabilities" to conduct

research on cognition and develop and disseminate new technologies to improve the quality of life and independent living of people with intellectual disabilities.

6) The AT Subcommittee promotes the development of models for delivering assistive technology to individuals with intellectual disabilities in transition from schools to post-secondary programs and/or employment.

Questions and Answer Session.

Mr. Lohff asked for clarification on point number five. Would this proposal be directed in helping people to better make use of whatever assistive technology equipment they might have?

Mrs. Coleman responded that it goes back to the issue of establishing models, what the model looks like and what support will be necessary to have the technology in the field. There is a mountain of technology that has never been utilized by people who have bought it. It has to be a huge factor in how we create these models.

Dr. Giannini commented that the NIDRR already funds a Center on Technology that focuses on people with cognitive disabilities.

Dr. Braddock clarified that there is not currently a technology engineering research center on cognitive disabilities, much less intellectual disabilities and technology at the Coleman Institute. Their Center is concerned with intellectual disability and mental retardation. They do not have the focus on technology.

Report of Subcommittee on Education and Transition.

Annette Tallis, Subcommittee Chair, presented her report via telephone. She made the following observations and recommendations on behalf of the Subcommittee on Education and Transition:

1. Priorities and high expectations matter in the education of students with intellectual disabilities.
2. Federal agencies should view services and supports for people with intellectual disabilities as a seamless preK-16 continuum.
3. K-12 teachers and postsecondary faculty must be trained to educate students with intellectual disabilities to meet high standards.

Focus Area I: The first recommendation fits within the framework of No Child Left Behind. The Subcommittee on Education and Transition has been involved in actual policy making in that arena already, as the No Child Left Behind Act is currently in place

and rules are being written. It's becoming more and more obvious to our other students that priorities and high expectations matter for students with intellectual disabilities, just as they matter for all students. We are not saying anything goes. We need curricular scope sequence and accountability in what's going on.

The mission of schools is to focus on building foundational skills, disposition and knowledge that leads to opportunities after grade twelve, including employment and post-secondary. Not everything goes in the classroom. The world of K-12 is going to be in skills, dispositions and knowledge. K-12 needs to be held accountable for that and we expect that accountability.

The Subcommittee's action plan on that is the status of standards and assessments right now. Educators are getting together, and have been for the past ten years or so, to decide what students should know. They aren't talking to business people that are going to employ these people. There aren't always direct, clear lines to even post-secondary or applied technical occupational training. The U.S Department of Education must collaborate at this critical time as we go off on this direction of standards and accountability. Skill dispositions and knowledge are relevant to working and ultimately to careers.

In 1991 the Department of Education and the Department of Labor put together the "Secretary's Commission on Achieving the Necessary Skills" sometime called the (SCANS) report. The initial report was called "What Work Requires of Schools." We need to break down the turf for educators and have work force federal officials talking to education as we are looking at the skills that open doors for people.

The collaboration between the Department of Education and Department of Labor starting with that SCANS report has some real foundational issues. When we looked at standards and assessments in education, everybody looked at reading, math, science, and social studies, because those are the barriers that we always had; those were our subject areas. What we didn't think about are the areas that open doors for people in all context of work.

The SCANS report looked at the solid foundation in literacy, computational skills, thinking skills necessary to put knowledge to work, and personal qualities that make workers dedicated and trust worthy. That's a good basis for thinking about standards and assessments and a universally designed system that applies to all students. I think we can create a bench mark that would apply to the range of learners.

The Education and Transition Subcommittee recommends that standard-based instruction be based on relevancy to the outcomes that we want. The Department wouldn't necessarily tell States what to do, but would develop best practices for sequential relevance systems of standards. Sequential is important because we have standards that can be scattered and measured, but what do the measurements mean? How far in literacy have you come if you know this skill, that's one recommendation?

At the U.S. Department of Education an intra-agency task force, including national experts with special knowledge of curriculum and instruction and others with knowledge of assessments, to provide ongoing, formal guidance to states was created. This all rolls out under No Child Left Behind. Let's keep monitoring it and improving it to get closer to the ideal outcome. The cross-cutting issues would be education and waivers getting together in a meaningful, effective way to pursue the development of universally relevant student performance skills and knowledge that relates to the world of work and post-secondary education and training, particularly with regard to the students with intellectual disabilities.

Focus Area II: The federal government must broaden its view of education and vocational services for students with intellectual disabilities to develop a seamless pre K-16 policy that unites K-12 public education, higher education and adult development disabilities services (vocational/rehabilitation, Medicaid, Carl Perkins, county, state) in a joint effort toward meaningful careers, postsecondary opportunities and employment outcomes.

Currently, the Individuals with Disabilities Education Act (IDEA) requires students with disabilities to be served until age 21, but this should not be limited to high school-centered services and supports. Nor should the seamless system merely add four grades to high school. Instead, blended adult funds and cross-agency efforts must begin when transition begins under IDEA. This collaboration must be more than a symbolic requirement for joint meetings. Everyone must be at the table with resources that are tied to employment as a performance measurement. Public schools should be prepared to provide students credentials, diplomas based on authentic assessment systems that measure the development of skills, dispositions and knowledge through the pre K-12 system that are relevant to employability and postsecondary (13-16).

Action Plan:

The Office of Management and Budget must hold the U.S. Department of Education, the Social Security Administration, the CMS and other agencies that provide funds to students and adults with disabilities or other learning challenges, to the same performance goal of achieving employment or postsecondary outcomes for students with intellectual disabilities. We proposed individualized services to students that address whatever learning and employment barriers there are. The best place and agency and person to address whatever the issue is, is the one that that one that should be applied to.

Focus Area III. This Focus is in regard to educator training and professional development. The Subcommittee is working with ex-officio members from the Department of Education on what a relevant action plan can be. We want to improve the quality of the teachers, educators, and administrators that are in schools and work with students with intellectual disabilities, provide adaptive methodologies and push standard base instruction.

Basically, the Education Subcommittee's recommendations are that federal policies should recognize that priorities and high expectations matter. We need qualified educators at our level of K12 and post-secondary. It's a new idea to think about adaptive specialists, or what we now call special education teachers, being in post-secondary environments. But that's going to need to happen if we want students with intellectual disabilities to get into those environments. We need to create those specialties in those educational arenas.

Question and Answer Session:

Michael Morris asked if the Subcommittee planned to include technology and education in its recommendations.

Mrs. Talis replied that in collaboration between the Department of Education and Department of Labor, one of the key things was what competencies are. What are the priorities? Technology and application of technology to the world of work is one of the key things that employers want in their employer environment. We would hope that looking through that technology, even though it's not the rigid science, math and reading curriculum, it's a priority item to the youth, particularly around cognition.

The Subcommittee will be providing technology related to post-secondary and employment that might not have been needed in the high school, but the Voc Rehab people will already be there at the table partly funding that so we can attach the technology to the person, and it won't be the artificial turf. Whatever the services are, one of the services would be assistive technology. We need to underscore that and then K-12 teachers in post-secondary faculty training where technology is a key adaptive strategy can help students with intellectual disabilities learn.

Ms. Lee congratulated the Committee on doing an excellent job of identifying and addressing key issues in Education for students with cognitive disabilities that would also benefit all students with other disabilities. She concurred that assistive technology will play a key roll as we develop universal design standards, curriculum, and assessment in structural materials.

Michael Rogers commented that under the No Child Left Behind Act, Special Ed seems to be less and less relevant. The focus is on whether one can teach, not if they are in Special Ed. He asked how to address having people in settings where they're out of the class room.

Mrs. Talis replied that education is what will be effective and will provide the services and supports. The only time that we are going to officially divide students is when we assess performance in relevant subcategories. When all students are aggregated together, some performance discrepancies can be missed. Placing a special emphasis on students with intellectual disabilities is a priority.

Dr. Appareddy posed a question to Ms. Lee regarding the failure of some States, especially Mississippi, to meet the requirements for the No Child Left Behind Act, and how that is going to be handled.

Ms. Lee conveyed that there has been a substantial increase in funds in the No Child Left Behind Act. Each State has submitted a plan on how they are going to implement No Child Left Behind. Their plans have been approved. Now they are working on plans that relate to the assessment that will be very important, particularly for children with disabilities. The State of Kansas had a tremendous focus on improving performance results for all children, including children with disabilities. They have had a dramatic increase in scores, approximately 26%.

One problem is that there is some back lash about children with disabilities. There are folks who are saying that schools are failing children with disabilities because they are below grade level. There is a real misunderstanding about who children with disabilities are and why they are identified. The latest draft data from the 26th Annual Report, which has not been released yet, shows that almost 60% of the children have learning disabilities. Those are children with typical intelligence or above average intelligence that have learning disabilities which need to be addressed. There are some specific issues regarding children with intellectual cognitive disabilities and there's another proposed rule making has been put out. The Committee has made recommendations for students with the most significant cognitive disabilities.

Report of Subcommittee on Family Services and Supports

Brenda Leath, Chair of the Subcommittee on Family Services and Supports, presented the Subcommittee's recommendations. She reported that comments and the Subcommittee's focus has been on looking across the life span on solutions to improve the quality of life for persons with intellectual disabilities and their families by: (1) enhancing services available to these individuals, and (2) promoting systems that afford easier and faster access to those services.

The Subcommittee had three major recommendations:

1. Convene a White House Conference in collaboration with the National Respite Coalition on model service approaches to respite care. Identify models and the problems they address. Solicit participation and responses from various private and nonprofit organizations. The Subcommittee would like to invite President George W. Bush to give an opening address.

2. Ensure that American families of individuals with intellectual disabilities have access to quality respite care services across the lifespan using block grant mechanisms to support State and local budget appropriations.

3. Fund demonstration initiatives designed to assess the efficacy of various respite care service prototypes provided by diverse types of community-based organizations to include faith-based, academic center-based and social service-based organizations.

Focus Area. The Subcommittee's next focus area is on Waiver Blending. This could have been an overarching recommendation because it has implications for all of the Subcommittees and cuts across various areas. The action plan here is to increase State flexibility for improving access to services by individuals with intellectual disabilities across their lifespan (from birth to death- including prenatal, universal newborn screening and end-of-life decisions).

Action Plan

1. Examine the feasibility of blending federal, state and local waivers (*i.e.*, CMS, SSA, HUD, DOT, DOL) to facilitate expanded individual choice and access to integrated community based-services by persons with intellectual disabilities. This requires exploring with the MB the opportunities for blending funding streams to support these demonstration initiatives and employing State incentives to reward demonstrated efforts to link Social Security with closing institutions.

2. Conduct demonstration initiatives in selected States to assess the impact of bundling waivers on such issues as individual choice/access to community-based services, family support services, assisted living and housing, transportation and earned income opportunities (cuts across Subcommittees).

3. Establish a technical assistance initiative on 1) effective State strategies in the use of HCB waivers; 2) provider service diversification including community-based and appropriate institutional-based care; and 3) successful State planning around the development of responsive services for persons with intellectual disabilities.

The Subcommittee thinks that it is very critical to help implement or expand the use of waivers which is currently a mechanism that can be used by States, but is not being used to the level that we would like to see it. The third is a very important and critical area for us; we're dealing with health, the health of the individual and looking at it from the eyes of those who have to provide services to them. Ensure that persons with intellectual disabilities are supported by competently trained and adequately compensated Health and Direct Support Professionals that they have access to comprehensive health care (Medical, Dental, Mental Health and Allied Services).

Recommendations:

1. Provide culturally competent, age and gender specific support based on psychological, medical, social and behavioral level of support needs. Steps to accomplish this recommendation should include:

- Training for Direct Support Professionals
- Removal of inequitable compensation between providers in State institutions and community based centers; and improvement in recruitment and retention of qualified Direct Support Providers.
- Creation of recognizable and portable career ladder (mentorship).
- Creation of uniform skill standards (nationally).

2. Training for Health and Mental Health Professionals:

- Establishment of a Task Force on Health for Persons with intellectual disabilities (See Appendix)
- Establishment of an interagency cooperative agreement program between such agencies as: the Centers for Disease Prevention and Control, the Bureau of Health Professions Training, the Administration on Developmental Disabilities, the Center for Medicare and Medicaid Services, and the Agency for Health Research and Quality to support the work of the Health Task Force and demonstration programs to facilitate implementation of Task Force recommendations in the US and US Territories.

3. Creation of opportunities for Fellowship Training.

- Expansion of the curriculum of the health, allied health, mental health and dental schools to include coverage of clinical management of issues for persons with intellectual disabilities, including under-graduate, post-graduate, and continuing education.
- Assurance that people with dual diagnoses of ID & mental illness, and their families, have systems that afford them adequate mental health services.
- Consideration of recommendations from professional organizations such as those listed below to help shape the development of training standards and content.

Strategies for Addressing Cross-Cutting Issues:

Education:

- Promote the health of students with ID so that they can be productive and successful in school.
- Incorporate appropriate provisions/ accommodations for students with ID in co-located school-based and school-linked health services.

Employment Services:

- Ensure access to affordable health benefits for workers with ID.
- Enforce and routinely monitor protections for workers with ID against occupational hazards.

Assistive Technology:

- Ensure the availability of adaptive equipment and assistive technology in clinical settings where persons with ID are treated.
- Ensure access to adaptive equipment and assistive technology for people with intellectual disabilities who need such supports to enhance their daily living.

Public Awareness:

- Promote the reduction and elimination of stigma and discrimination against persons with ID in all health service delivery settings.
- Promote self-care and wellness programs aimed at avoiding health risks and understanding effective personal management of health needs that can prevent chronic and debilitating illnesses.
- Promote increased visibility of health and ID research.

Report of Subcommittee on Public Awareness:

Kim Porter Hoppe, Chair of the Subcommittee, presented her Subcommittee's report, including recommendations. She noted that the Public Awareness Subcommittee convened a Roundtable with many of its members, professionals from the outside world, advertising agencies and public relations firms. One thing that came out of the Roundtable is that we need a very concise, specific message that may have one or two prongs specifically about attitudes. She stated that attitude has got to change. The message has to be blunt and specific. Something that we forget to say when we were talking about people with intellectual disabilities is that we are talking about Americans who happen to have intellectual disabilities; it's not just about people with Intellectual disabilities. It's really about everyone.

The Public Awareness Campaign will start very specifically with target audiences in three specific areas. (1) Schools. We want to do something that is dynamic; we start out with skills and do attitude awareness piece with the schools. (2) Work and employment. We will propose a very specific way of working with employers. It would be totally free, wouldn't cost any agency a dime to get employers excited about working and collaborating with people with intellectual disabilities. (3) A combination of both. The main venue that we would like to use is through an advertising campaign, very reasonably put together, asking the community to buy into this with their own individual tag line.

The Subcommittee will be looking at putting together some sort of marketing campaign as well as a tool kit for various organizations and other media print and radio. We have found people who are willing to help us put together this campaign. One of the things we want to recognize are employers that were successful in hiring people with intellectual

disabilities. We were very impressed with Nancy and Dr. Radar's presentation on a multi media campaign, a different kind of Annual Report, but felt that it may cost a little too much. Let's make sure this Annual Report is the very best that we can offer to our President.

Question and Answer Session:

Ms. Lee complimented the Subcommittee on its recommendations and shared a couple of things. One of the things that Education found in doing the OSEP research is that disability awareness with school aged children is important. If it could be directed towards encouraging specific interaction between children with and without intellectual disabilities, that's what changes their attitudes - when they have the opportunity to be in school together. To be in extra curricular activities, not just sitting in the same room, but structured supported interactions. Since that Roundtable, at the request of Special Olympics, the OSEP has made an award to Gary Seiperstein to evaluate the Special Olympics curriculum to see if it really is changing attitudes.

Jim Brett asked how to raise money to advertise.

Mrs. Porter-Hoppe said that the Subcommittee is very concerned with how to get the money and has discussed partnering with agencies and public organizations to accomplish PCPID's goals. Several groups have come to the table and stated that they would like to partner with us. For example, *Exceptional Parent Magazine* has offered to partner with us. The money will follow.

Report of Subcommittee on Employment

Ed Mambruno, Chair of the Employment Subcommittee, and other members of the Subcommittee presented their report and recommendations.

Mr. Mambruno emphasized the point that the Employment Subcommittee's mission is to uphold the rights of all persons with intellectual disabilities to enjoy meaningful employment, a quality of life that promotes independence, self determination, and participation as productive members of society. The first recommendation is a dual waiver, partly modeled after the Independence Plus Waiver of Florida. Mr. Mambruno asked Ken Lohff to take the floor and explain recommendation.

Ken Lohff provided an explanation of the dual waiver, which he said precedes Jim Brett's idea of an asset accumulation account. In order for that program to operate, it would require the lifting or waiving of limitations on the accumulations of personal assets. The asset accumulation limit is \$2,000 for most recipients of Social Security and Medicaid benefits. If the project that is being proposed would have savings accounts, possibly as much as \$10,500 or \$11,000, the dual waiver concept is there. Two agencies influence or impact upon the asset limitation – the Social Security Administration and the

CMS. We would need to effectively get permission for the asset accumulation caps from both of those agencies in order for this program to function.

Mr. Gross discussed the second recommendation, which is to pass legislation establishing the qualified disability savings account. At the last full meeting, the PCPID members voted to explore the options of creating an IDEA plan for persons with intellectual disabilities with other relevant federal Agencies. Mr. Gross reiterated details on how the qualified savings accounts would work.

Mr. Aponte presented the Subcommittee's recommendation for establishing a strategic partnership to promote employment in conjunction with the Department of Labor and the Department of Commerce, with equal assistance and involvement of The Equal Employment Opportunity Commission (EEOC) to promote employment and establishing business for training people.

The EEOC has the enforcement portion. They protect the civil rights of individuals, the right of employment and to avoid discrimination. Most individuals with intellectual disabilities are not employed because of lack of training, lack of opportunities, lack of direction, and discrimination in employment. Mr. Mambruno noted that establishing this strategic plan, corporation, or alliance partnership will serve the purpose of PCPID using the mechanism of the Awareness Campaign to actually convey the message to families and consumers.

Mr. Gross explained that the Subcommittee has a piggy back recommendation and a strategic plan that allows a person with an intellectual disability to have many options to find work.. We are removing the obstacle of eliminating their benefits. Creating a savings account and partnerships with federal agencies will assist with all the resources and help the Subcommittee in developing plans to assist people with intellectual disabilities in finding employment and to be self supportive.

Question and Answer Session:

Ms. Lee asked for clarification on whether an individual with a disability himself could contribute to the savings plan or would only the family be eligible?

Mr. Gross said that the Subcommittee will have to look into the individual portion of that.

Ms. Lee raised the issue that some individuals with disabilities receive SSI and Medicaid and some receive DI. A family has to be very wealthy to have a child with intellectual disabilities and health problems to privately support them throughout their life. She recommended raising the savings limitation to a higher than \$11,000.

Mr. Gross liked the idea, but thought that by getting into the tax area and increasing the limitation, it would bring in a lot of other individuals and create a loop hole that we didn't want to get too messy.

Mr. Lohff stated that the \$11,000 is tied into the gift to the beneficiary without filing a tax return.

Ms. Lee expressed concern about a third party being the intermediary for the funds.

Mrs. Staley asked that the issue of jobs outsourcing not be dropped. Ms. Will advised members that the Committee has sent letters to agencies and assured her that the issue would not be dropped.

Mrs. Will thanked the Subcommittee Chairs for their reports. She asked that all the reports be typed so the members can review them before they vote. She proposed that lunch be shortened a little so that the Committee would have time to vote on the recommendations.

Michael Rogers had to leave early to catch his plane, and asked to vote by proxy. He appointed Michele Tennery as his proxy.

Mrs. Will asked the new ex-officio representatives to introduce themselves.

Johnny Burton introduced herself as the representative for Secretary Norton of the Department of Interior. Mrs. Burton is Director of the Minerals Management Service. She was asked to be the representative because of her experience in sitting on Boards of Education and being a trained teacher. She has a son who suffered brain injury at sixteen. He is now an adult and she is trying how to help him integrate into society.

Bryna Helfer introduced herself as the representative from the Department of Transportation on behalf of Secretary Mineta. She is an advisor at the Federal Transit Administration on Human Service Transportation. Coordination with other agencies is active and she is excited about the Department's work with the Office on Disability, the Department of Education, and the Department of Labor.

Discussion of Public Awareness Campaign

Neil Romano, The Romano Group

Mrs. Porter Hoppe introduced Neil Romano of The Romano Group. Mr. Romano has served as a guest lecturer for Eagle University, an extensive, hands-on leadership seminar held on college campuses throughout the United States. He currently resides in Clarksville, Maryland, with his wife Barbara and two daughters, Bianca and Christina. Mr. Romano volunteered to assist the CPID with its Public Awareness Campaign.

Mr. Romano emphasized his dedication to helping people with disabilities and his gratitude for being invited to assist in the Public Awareness Campaign. He stated that he

has struggled with a very serious intellectual disability throughout his life. He is dyslexic.

He observed that the size and messaging for a Public Awareness campaign is different for each audience. Not everyone will agree on the message.

Mr. Romano discussed the public's perception of people with intellectual disabilities. In the field of education people with intellectual disabilities are viewed as nothing more than petulance. In the area of employment, people have an aversion to what a person with intellectual disability looks, feels, and smells like. The media and the entertainment world call these people "retards," showing them in the worse possible light.

Mr. Romano discussed a strategy for developing the campaign, which is to go to the "belly of the beast." The issues the PCPID is faced with are issues that shouldn't be taken any less seriously than the civil rights issues in the 50's and 60's. We must let the public know that these are people with intellectual disabilities who have hope and fears, loves, and wants, and needs, just like others.

He relayed overhearing a conversation his principal had with his mother: "He's retarded; forget about it. He's not going anywhere except where he is and let him be what he is." He remembers his high school guidance counselor saying "Neil, do me a favor, please. Don't waste you parents \$15 on the application for college."

Mr. Romano discussed possible messages that the PCPID could use. It has to be a pointed message that will get attention. For example, "I Am a Human Being. I don't want to be treated as anything more than you. I am a human being whether you like it or not; accept the fact that I'm a human being. If you don't accept it, then it's your problem."

That's the kind of message that can be incorporated into virtually any kind of program. The PCPID has a tremendous opportunity to really do something dramatic in this country.

The two areas that need the most help are education and employment. Mr. Romano suggested three basic public service announcements around education. The education message would be something to the effect of "What do you want for your child? I want the same thing for my child. That's all, you are a mom; you are a dad, and I'm a dad. I want the same thing you want."

For employment, it's an even more basic message. An employment message folds more around the category of "We are not looking for a break, we are looking for a job. I don't want a break, and what I would like you to do as you look at me give me an opportunity to show you what I can do as opposed to assuming that I can't do anything." The message is "Find out what I can do; I'm a human being. Don't look at me for what I can't do."

Mr. Romano suggested partnering with organizations at the national level, such as NBC, ABC, CBS, and Fox TV. The PCPID will need to develop a message, develop things, and develop a TV piece. Develop these pieces for every group and field working in the area of intellectual disabilities along with a tool kit that shows them how to get this stuff on the air, how to talk about it, and how to make the message their own.

Mr. Romano also suggested developing an award that goes to corporate people. People fight for excellence in their corporations so they can get that award; develop a website so that if a small employer with 50 or 60 people is looking to hire someone with intellectual disability, he will know where to go. The basis of the program is to come up with a great message, take your spots and not be initially concerned about money. The funding will follow. Get the program together. Write the business plan first, and know what we want to do.

Question and Answer Session:

Mr. Gross asked if the aim of that commercial is to inform, to educate, or to show a disability of the person.

Mr. Ramamo replied that it depends on the target audience. It will hit them in different ways. For some people, it will inform them; for others, it will be "I'm aware of that and maybe I can do a little bit more;" and for others, it will be "maybe I should think about this." Yes, it is a design to make people uncomfortable.

Mrs. Will asked if making people feel uncomfortable in order to understand something is sufficient. Does that, in and of itself, produce behavior change?

Mrs. Porter-Hoppe stated we need to get back to the basics of educating Americans about people with intellectual disabilities. If we stop seeing these people, we start assuming that everybody else has taken care of them. This is a very specific picture that Public Awareness needs to address.

Mrs. Staley mentioned that the Subcommittees didn't have enough time to review all the materials they had received, and get down to what they wanted to recommend. She suggested advance meetings.

Mrs. Will said that the Committee would not have time for advance meetings because it had been invited to an "Emerging Workforce" Conference in Florida, and that the Committee probably should have its next quarterly meeting during that time in February. She asked Milton Aponte to explain the Emerging Workforce Conference to the members.

Mr. Aponte discussed the basics of the conference, which is organized by parents like himself, his wife, and other similar advocates in South Florida. The purpose of the conference is to offer employers, consumers, and providers the opportunity to come

together and explore the possibility for employment. Registration begins on Sunday, February the 8th. The conference will be held on February 9th and 10th. Governor Bush is a key speaker on the 9th of February.

The National Council on Disabilities is having a meeting at the same hotel on the same day. The Access Board and the Ticket to Work have agreed to have their regular quarterly meetings there at the same time. The President of the United States has been invited to attend and address the group. The website for Life Inc, the organization presenting the conference, is www.life-fl.org.

Mrs. Staley mentioned that her term expires in May 2004, and asked if there is something that she should be doing to be reappointed.

Sally Atwater provided the name of a White House contact, Laura Keehner, and suggested that members contact Laura. Laura's telephone number is 202-456-2893.

Mrs. Will reminded members that the meeting in May, 2004 will take a considerable amount of time because several members, whose terms expire, will have to be sworn in again.

Mr. Stallings expressed his concern about the ability to work on Committee issues if the next meeting were held in Florida.

Mrs. Will said that we will do what is the will of the Committee. It is possible that the Committee will send a small group rather than the full Committee.

Mrs. Staley inquired about the process for getting reappointed to the PCPID since her term will expire in May, 2004. Sally Atwater suggested that members and their original nominators send a letter of interest to the White House, with a copy to the PCPID.

Discussion of Subcommittee Recommendations

The Committee has produced 20-25 recommendations. Mrs. Will asked that the members read over the recommendations so they could go forward and come to some consensus about what we want to do. It may be possible to bundle some recommendations.

Dr. Radar offered to do a spread in his magazine (*Exceptional Parent*, of sixteen pages. The report must have a forward, a summary page, and a listing of Committee members, which will make it a little larger.

The members then discussed the number of recommendations, focus areas, a glossary of terms, executive summary and a theme for the report. It was agreed to capture a central theme that can use all of the Subcommittee recommendations.

Michael Rogers asked that the final report also be put on a disc.

A discussion ensued on whether the audience of the report would be the public or the only the President. Mr. Gross said that the real function of the report is to inform the public about the Committee recommendations and that the Committee should not be thinking about the audience as the President. Mr. Lohff and Mrs. Porter-Hoppe felt that the President or one of his aides would read it and, therefore, it should be the very best product that it can be.

Mrs. Will asked Ms. Lee if there is any technology that we could use with respect to the two page summary of the recommendations to make it accessible for persons with intellectual disabilities so that we can model what we are asking for.

Ms. Lee will work with Michael Morris on that issue. She mentioned that, as far as Assistive Technology is concerned, there is a free reader for people with cognitive disabilities and people who are visually impaired and/or blind. Once we put the product into text, it can be put on a CD and people will be able to read that information.

At the request of Mr. Gross, Laverdia Roach talked about earlier reports by the Committee, where they have gone and the effect they had. Ms. Roach said that the Annual Report is the only thing that the Committee is mandated to do, because it is mandated by Executive Order of the President.

Until several years ago, the President received the Report through the standing Chair, who was the Secretary of Health and Human Services. The Report has always been printed in volumes not less than ten thousand copies. It is a public document that goes to constituency groups (many of whom assist in the dissemination process), advocacy organizations, institutions of higher learning, state governmental agencies, and private foundations.

Initially, President John F. Kennedy, in spite of his considerable fiscal resources, could not access appropriate supports and services for his sister who was diagnosed with mental retardation. So, he created a blue ribbon panel to study mental retardation. One of the recommendations in the Panel's Report to President Kennedy was that a President's Committee on Mental Retardation be established.

The first charge in the Executive Order is to evaluate the adequacy of the national effort to improve quality of life. Issues or focus areas must be identified. An Executive Summary is also required to include an action plan that helps the President and others understand how to make things better for people with intellectual disabilities.

Next, the Report must suggest some objectives that are measurable for future generations. Although the current Committee's Annual Report will be submitted in the spring of 2004, it is, in essence, perhaps the most popular Report that the President's Committee has prepared since the *Century of Decision* was published.

The Committee's Report to the President must also address the new era, the New Freedom Initiative, and anything that represents a kind of blueprint, if you will, for the future.

One other pivotal point in the history of this field, perhaps the most catalytic action ever taken by a President, was that taken by President Nixon. He invited Americans to do a couple of things: (1) to assist in the effort to deinstitutionalize, (2) to reduce incidents and prevalence rates.

Mrs. Will pointed out that the estimated cost for producing the Annual Report is \$70,000

Ms. Roach next discussed the process for publishing the report. There are five phases in the process which may vary tremendously in cost, depending upon who implements each phase. The Office of Public Affairs (OPA), in the Administration for Children and Families, committed to do the editing and printing. This would bring the cost down by thousands; but that commitment was for the last fiscal year. Because the Report was not ready to be printed from OPA's budget for last year, this office is no longer able to do honor that commitment. That adds to the dollars.

Until recently, much of the work into the Annual Report was done, gratis, by persons in the field of mental retardation, such as David Braddock and others, whose reward was recognition as the editor, writer, and preparer of the Report. The cost estimate is relatively modest.

Vote on State of Recommendations

Mrs. Will asked the Committee to come to some kind of consensus on the recommendations, design and publication of the report.

Ms. Leath made a motion that members take one Subcommittee at a time and vote on the each of their recommendations. The motion was approved.

At the suggestion of Mr. Solomon, the Committee agreed to pick two or three of the most global issues from the Committees' recommendations and highlight those as both talking points and action points for the President to consider.

Recommendations of Subcommittee on Assistive Technology. A motion was made and passed to accept the recommendations of the Subcommittee on Assistive Technology.

Recommendations of Subcommittee on Education and Transition. Kim Porter-Hoppe moved that the recommendations from the Education Subcommittee be accepted.

Recommendations of Subcommittee on Employment. A lengthy discussion was held regarding whether to add language on funding for Focus Area III in the recommendations of the Employment Subcommittees.

Dr. Bouthilet conveyed that the PCPID is not a funding agency and cannot partner with the Department of Commerce, the EEOC or any other agency, as far as money is concerned. The OGC has indicated that any funds must remain in the department and issued by that department. There are no transfer funds.

It was agreed to amend recommendations of the Employment Subcommittee by adding language on a strategic partnership for employment for people with intellectual disabilities between the Department of Labor, Department of Commerce, and Department of Education.”

A motion was made and seconded to approve the recommendations, as amended.

Recommendations of Subcommittee on Family Services and Supports. A motion was made and approved to accept the recommendations of the Family Services and Supports Subcommittee.

Recommendations of Subcommittee on Public Awareness. Mrs. Staley asked that the records reflect that the Committee accept the recommendations of the Public Awareness Subcommittee, even though there was not written report.

Members of the Committee discussed adding a separate recommendation on performance measures.

Ms. Lee moved that the Committee work on further developing a proposal for accountability performance measures and incentives, and come back to the Committee with details. The motion was seconded.

The recommendations of the Public Awareness Subcommittee were approved as discussed.

Committee Dialogue on Scope of Annual Report

Members discussed the importance of accountability and performance measures for the employment of people with intellectual disabilities. They also discussed creating a task force between the OMB and the PCPID and other important agencies that administer programs affecting persons with disabilities.

Ms. Lee moved that that the Chair works on further developing a proposal for accountability performance measures and incentives and report back to the Committee. The motion was approved.

It was agreed to link the Report into the President's New Freedom Initiative and that the title of the report should somehow reflect that.

Presenter/PCPID Dialogue

Mrs. Will asked from the Committee on success stories that have been presented for inclusion in the report.

Michael Morris stated that before using any success stories, the Committee must first get releases from the individuals. We also need pictures and it is important to find out what funding streams facilitated the success stories and to identify the barriers that slowed the individuals down.

Next Steps/Action Items

Budgetary constraints and format were discussed. Sally Atwater commented that the PCPID is still operating under a continuing resolution and that it probably would not be extended until mid-February. The Committee will explore all of it before voting on a format.

Dr. Rader offered to put the picture of the Committee members taken in the President's Oval Office in the centerfold of *Exceptional Parent*.

A draft of the Report must be completed by mid-December. Copies will be sent to all members for review and comment. Those comments will be incorporated in a second draft. A final draft will be disseminated again to the Committee members who may approve or disapprove. The members vote, usually approve it, and it goes to print.

Wrap-Up

Mrs. Will said that she hopes to have the Report printed in April or May 2004. Budget issues and format will be discussed by telephone conference prior to the next quarterly meeting. She thanked the members and presenters for their contributions and comments.

The meeting was adjourned at 3:30 p.m.

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Note: Due to errors in recording, some of the discussions may be missing.

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The transcript of the meeting is available upon request.

