



MINUTES

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

**Quarterly Committee Meeting
January 31, 2005 and February 01, 2005**

**6th Floor Auditorium East
Aerospace Center Office Building
901 D Street, S.W.
Washington, D.C.**

ATTENDEES: 18 Citizen members and 13 ex officio members were present. One citizen member participated by audio conference.

PCPID Civilian Members:

Vijaya L. Appareddy, M.D.
Nancy C. Blanchard
James T. Brett
Mary C. Bruene
Claudia L. Coleman
Olivia R. Colvin
Zoraida F. Fonalledas
Kathy Hargett
Brenda A. Leath
Kenneth E. Lohff

Edward R. Mambruno (via Telephone)
Alvaro A. Marin
Michael J. Rogers
Windy J. Smith
Reverend Lon R. Solomon
Karen L. Staley
Gene C. Stallings
Annette M. Talis
Madeleine C. Will, Chairperson

PCPID Ex Officio Members:

Margaret Giannini, M.D., F.A.A.P.
Representing The Honorable Michael O. Leavitt
Mark Gross
Representing The Honorable John Ashcroft
Patricia Arnaudo
Representing The Honorable Alphonso Jackson
Rejane "Johnnie" Burton
Representing The Honorable Gail A. Norton
W. Roy Grizzard, Jr., Ed.D.
Representing The Honorable Elaine L. Chao
Nancy Skaggs
Representing The Honorable Elaine L. Chao
Susan Goodman
Representing The Honorable Jo Ann Barnhart
John P. Benison
Representing The Honorable Norman Y. Mineta
Claudia Gordon
Representing The Honorable Michael Chertoff
Mary Kay Mauren, Esquire
Representing The Honorable Cari Dominguez
Milton Aponte
Representing The Honorable Lex Friedman
Marci Hunn
Hank Oltmann
Representing The Honorable David Eisner

PCPID Staff:

Sally Atwater, Executive Director
George Bouthilet, Ph.D., Research Director
Laurice Redhead, Administrative Assistant
Laverdia Roach, Special Assistant to the Exec. Dir.
Lena Stone, Program Specialist
Sheila Whittaker, Budget Officer

Guest Speakers:

Stephen S. Allen
National Community Lending Center
Fannie Mae

Susan Banks
National Native American
Families Together Parent Center

J. Michael Bibo
Mental Retardation/Developmental Disabilities
American Health Care Association

Jeremy Buzzell
U.S. Department of Education
Rehabilitation Services Administration

Steve Bruce Corbin, DDS, M.Ph.
Special Olympics, Inc.

Curt Coy
Deputy Assistant Secretary for Management
Administration for Children and Families
U.S. Department of Health and Human Services

Chris Curry
National Native American
Families Together Parent Center

Berthy De La Rosa-Aponte
Ticket-to-Work and Work Incentives Panel

Sanford J. Fenton, DDS, M.Sc.D.
University of Tennessee
College of Dentistry

Margaret J. Giannini, M.D., F.A.A.P.
U.S. Department of Health and Human Services
Office on Disability

John Hager
U.S. Department of Education
Office of Special Education
and Rehabilitative Services

Amy Hewitt
Institute on Community Integration

Hal Lippman
Joseph P. Kennedy, Jr. Foundation

Wendy M. Nehring, RN., Ph.D., FAAN
Rutgers, The State University of New Jersey
College of Nursing

Grayson Noley
National Native American
Families Together Parent Center

Steve Perlman, DDS
New York University

JoLeta Reynolds
U.S. Department of Education
Office for Special Education and
Rehabilitative Services

Kim Romine
U.S. Department of Health and Human Services
Administration for Native Americans

The Honorable Ed Sontag
U.S. Department of Health and Human Services
Administration and Management

Guests:

Maura Archambault (Fragile X Foundation)
Camina Davis (OoD)
David Fleischman (HUD)
Lisa Godfrey (TLC)
Darlene Goggins (HUD)
M. L. Oster Granite (NICHD)
Hal Lippman (Kennedy Foundation)
Hank Oltmann (CNCS)
Ellie Runkle (TLC)
Tammy Snyder (TLC)
Michele Tennery (HHS)
Stephanie Tevenal (SLA)
Abby Warfel (TLC)

MONDAY, JANUARY 31, 2005

The quarterly meeting of the President's Committee for People with Intellectual Disabilities (PCPID) was convened at 9:09 a.m. on Monday, January 31, 2005, in Washington, DC. The purpose of the meeting was to receive presentations from invited speakers, conduct hearings with speakers and consider new focus areas for a Report to the President.

Opening Statements

The Chair announced that the agenda had been amended to accommodate the presentations of several speakers invited to the meeting.

A member inquired as to the status of interest in the five new focus areas being considered by the Committee. The Chair called for action by the members to finalize their interest in focus areas if they had not already done so.

The Chair called for comments and approval of the minutes of the previous quarterly meeting. A member indicated that her name was missing among the list of attendees at the last meeting. The Chair ordered that the minutes be corrected accordingly.

In response to a question by a Committee member, the Chair commented on the constraints of implementing recommendations in the Report to the President. The Chair stated that the President has up to one year to respond to the recommendations listed in the Report. Once there's a decision from the President, the Committee may openly support the wishes of the President.

A member noted that the Committee's termination date in the Executive Order and Charter is September 30, 2005. The member inquired as to possible action that may be needed to ensure continuation and adequate funding for the Committee.

A staff member advised that the President decides on the continuation of the Committee and gave responsibility to the Secretary of Health and Human Services to provide housing and administrative support to the Committee. Sally Atwater, Executive Director, is the "Designated Federal Official" for the Committee. She possesses the authority to request the status of continuation and funding for the Committee.

The Chair asked if the Committee should follow the same procedure for any additional changes in the language of the Executive Order or the Charter. The staff member replied in the affirmative. The Committee may offer suggestions for amendments but the changes must comply with the Federal Advisory Committee Act (FACA).

The Chair announced corrections to the minutes as requested and asked for a vote on the corrected minutes. The minutes of the previous meeting were approved by the Committee.

The Chair announced that JoLeta Reynolds was asked to provide an overview of the IDEA Reauthorization of 2004 and the plan for development of its regulations. Ms. Reynolds heads a policy team in the Office of Policy and Planning in the Office of the Assistant Secretary for Special Education and Rehabilitative Services of the U.S. Department of Education.

IDEA Reauthorization

On December 3, 2004, the President signed into law the reauthorized legislation for IDEA. A number of areas were noted in need of clarification before becoming part of the regulations. The members of the Committee were asked to review and consider items for inclusion in the regulations. The schedule for public meetings was announced in a handout that was distributed to members. It was suggested that the members look at the legislation through the statute website of the U. S. Department of Education. The presenter called to the attention of the members some key areas and cited sections of the statute that required special attention by the Committee.

The Chair of the PCPID Subcommittee on Education asked if it would be appropriate to pull out the recommendations in the Committee's existing report and forward them to the U.S. Department of Education during the comment period since the Committee has already voted upon them. The Chair replied that the Education Subcommittee should incorporate the suggestions in a letter. The Chair of the Education Subcommittee would work with the members of the Education Subcommittee to draft a letter to the U.S. Department of Education.

The Chair introduced The Honorable Margaret Giannini who serves as the Director of the Office on Disability

in the U. S. Department of Health and Human Services. The Chair announced that Dr. Giannini would brief the members regarding important developments from the Office of Disability.

Briefing on Office on Disability 2004 Initiatives:

Dr. Margaret Giannini stated that a month after President Bush took office he created, by Executive Order, the New Freedom Initiative (NFI) mandating that all federal departments tear down barriers for persons with disabilities. The NFI included provision for an office on disability. The White House and Secretary Thompson decided on housing the Office on Disability in the U.S. Department of Health and Human Services.

The new Office on Disabilities was given authority over all federal departments for assembling information and coordinating related activities. The Office on Disabilities was also given authority for coordinating information with the states and local government agencies. Domains for the New Freedom Initiative pertained to health, education, community-integrated services, employment, transportation, assistive technology, and home ownership.

The Office on Disabilities prepares an annual report to the President called, "Delivering on the Promise." The Office assures involvement of federal departments collaborate, partner, and address specific initiatives. The Office's role impacts on legislation and policy that improves supports for persons with disabilities.

The Chair introduced the next speaker, Jeremy Buzzell, a Program Specialist for the Rehabilitation Services Administration (RSA) in the Office of Special Education and Rehabilitative Services (OSERS) at the Department of Education. Jeremy spoke on the Assistive Technology Act of 2004.

The Assistive Technology Act of 2004:

Jeremy Buzzell stated that the Assistive Technology Act was signed into law by the President on October 25, 2004, to provide states with financial assistance that supports programs designed to maximize the ability of individuals with disabilities to obtain AT devices and AT services. The Act provides grants to states to maintain statewide AT programs to help individuals with disabilities to obtain assistive technology devices and services. These statewide AT

programs are supposed to be a central entity to help individuals with disabilities, professionals, or organizations get information they need to make assistive technology accessible.

An AT device is any device that improves or maintains the functional capabilities of individuals with disabilities. AT services are similarly inclusive from anything from evaluation to the customization of devices to the coordination of services related to AT to training and technical assistance. All 50 states and territories, D.C., Puerto Rico and the Virgin Islands, receive a grant and have a statewide AT program. Alternative financing programs go to states to set up a financial loan program, where persons with disabilities may get a guaranteed loan to obtain assistive technology device or services.

The National Institute for Disability and Rehabilitation Research recently funded a rehabilitation engineering research center at the University of Colorado to focus on cognitive disabilities. They are doing a large-scale nationally representative study of AT needs and AT usage amongst individuals with intellectual disabilities, and they're going to develop products.

The Chair of the Subcommittee on Assistive Technology inquired about sending a letter outlining some of the areas that the Committee was interested in. The Chair of the Committee stated that this would be a good task.

The Chair introduced the next speaker, Ed Sontag, Assistant Secretary for Administration and Management in the U.S. Department of Health and Human Services.

Remarks on PCPID Report to the President:

Ed Sontag stated that the Report to the President prepared by the Committee will provide a great deal of guidance for the field. He acknowledged that he was impressed with the companion document. He stated that this Committee has raised the bar for students with intellectual disabilities.

The Chair introduced a visitor, Curt Coy, Deputy Assistant Secretary for Administration, Administration for Children and Families, U.S Department of Health and Human Services.

Administration for Children and Families:

Curt Coy indicated that he has been in the government for about three years and has seen the work of the Committee. He congratulated everyone on the outstanding report and the companion piece that was issued for people with intellectual disabilities. He related that he dropped by to say "hello" and to tell the members, if they have any issues, the ACF will see what it can do to make sure that they are resolved.

The Chair introduced the next speaker: John Hager, Assistant Secretary for Special Education and Rehabilitative Services, OSERS, U.S. Education Department.

Remarks Regarding Priorities in OSERS:

John Hager indicated that he has established three priority areas for OSERS, including special education, rehabilitation, and research and technology: 1) reaching out and making OSERS more user-friendly, having a more visible program, and an outreach program that says that OSERS is doing something; 2) working on employment and work issues, and partnering with Labor because it is employment that is the linchpin that leads to healthcare, housing, transportation, and everything else; and 3) partnering with agencies in the federal government and outside organizations like the National Organization on Disability.

OSERS is dedicated to streamlining and improving the effectiveness of assistive technology. In the Rehabilitation Services Administration, the workforce training legislation is on the Hill for reauthorization. OSERS is focusing more on transition and lifelong approaches through its Office of Special Education.

The Chair called on Brenda Leath, member of the Committee, to introduce the focus area of Comprehensive Health and Long Term Care.

FOCUS AREA DISCUSSION - Comprehensive Health and Long Term Care for People with Intellectual Disabilities

Brenda Leath introduced the contextual framework for the current session based on health disparities. Although statistics reveal that people with intellectual disabilities are living longer than their counterparts in the 1900s, data revealed the existence of significant health disparities with regard to

health status, service availability, access, affordability, and quality. The causes for these disparities are influenced by multiple factors and often impact personal well-being and productivity. As we strive to achieve improvements in quality-of-life issues across the lifespan, we must consider how an individual's health influences one's ability to reach their maximum potential in the area of school, work, or leisure. It is important to make comprehensive healthcare a priority and to integrate effective solutions across disciplines and settings.

The first speaker for this focus area was Mr. Michael Bibo, Vice Chair for Residential Services of the American Healthcare Association.

Long Term Care:

Michael Bibo stated that he was the Government Relations Director for an organization that provides residential programs involving Medicaid waivers, home and community-based waivers and ICF-MR programs to over 1,500 individuals in the State of Illinois. There is still a population out there of severe and profoundly disabled individuals that need to have services provided for them.

American Healthcare is providing care and services to our nation's people who are frail, elderly and disabled. The American Healthcare Association (AHCA), and the National Centers for Assisted Living (NCAL), represent more than 10,000 nonprofit and for-profit providers dedicated to continuous improvement in the delivery of care for citizens who are frail, elderly, or who have disabilities and live in nursing facilities or assisted living residences, and citizens with intellectual disabilities who live in community intermediate care facilities for persons with intellectual disabilities and in group homes under the Medicaid Waiver Programs.

Brenda Leath introduced the second speaker on comprehensive health care, Dr. Wendy M. Nehring.

Comprehensive Health Care:

Dr. Wendy M. Nehring commented on the publication from the Surgeon General's Conference, *Healthy People 2010*. She emphasized the need to attend to this topic. The first point made was the need for a definition of disability. AHRQ's Healthcare Disparities Report, published in 2003, had a section on persons with

intellectual disabilities and highlighted some of the beginning information being gathered from national surveys. The American Academy of Pediatrics, with AHRQ, has begun to publish those results so that we have some definite data on health disparities in children.

Healthcare professionals are being asked by the public that their practice be based on scientific and research evidence. When we're looking specifically at persons with intellectual disabilities, we don't have a lot of information that will help us provide them the best care. We decided on the following health promotion topics, based on what was believed to be of most interest to our population: Hypertension; obesity; respiratory health; epilepsy; mental health concerns; and health in the school setting.

The Chair called on James Brett, member of the Committee, to introduce the focus area topic of dental care for people with intellectual disabilities.

FOCUS AREA DISCUSSION - Dental Care

James Brett stated that oral healthcare for people with intellectual disabilities is a serious problem and it is so for many reasons, whether it's reimbursement of Medicaid, the administrative bureaucracy, or appointments that have been frequently cancelled.

Dr. Steve Corbin was the first speaker. Dr. Corbin serves as Dean of Special Olympics University.

Presenter Statements:

Dr. Steve Corbin stated that issues on financing are a central problem. You must (1) have prepared professionals, (2) have adequate financing, and (3) have patients that are ready, willing, and able to go. If we look at it from those three dimensions, we'll have an idea of where we need to spend our time.

We might be able to identify an administrative or an advocacy option that we might pursue that could make a difference. How can we seize what's already there and use it in a way that could make a difference for the population that we care about?

Government agencies don't always understand the unique problems in this population. We find that 12 percent of our athletes that we screen on a given day will

report that they have some kind of pain. We see gross, oral disease needing treatment in this population.

James Brett introduced Dr. Sanford Fenton, a professor at the University of Tennessee.

Presenter Statements:

Dr. Sanford Fenton stated that if one doesn't have good oral health, one doesn't have good general health. Our goal should be to get our population to a point where comprehensive, conservative dental care will reduce the level of emergency care. *Closing the Gap*, from the Surgeon General's conference in 2001, showed that dentistry was one of the greatest unmet needs in the population of persons with intellectual disabilities. We can take care of the children, but they're aging and graduating from our practices and there's no mechanism in the transition for them to receive the adult services.

One issue is training and the other is a reimbursement issue. There are not a lot of individuals in the field who have either expressed a willingness or who feel comfortable in treating the population due to a lack of training. We could do more if we could allow them some loan forgiveness if they are willing to pick up a part of this patient population and provide services.

Insurance doesn't help us. For every child under the age of 18 without medical insurance, there are two kids who don't have dental insurance and scores of adults over 18. For every adult 18 or older without medical insurance, there are three adults without dental insurance.

The Chair asked James Brett to speak about the Report and how to involve the press. The Chair felt the Committee should do anything and everything to make people more aware of the Report.

Presentation on "Sound Bites":

James Brett stated he was successful in securing space on the Op Ed Page of the *Boston Globe*. To get an article printed in a major newspaper like the *Boston Globe* is quite challenging. It is very competitive because there's only so much space available. The press usually reserves only one column of a newspaper for guest editorialists to write an article.

Jim Brett revealed that he tried to identify an issue that no one had written about. We arrived at a subject that would make people stop and think twice about the economy in New England. We talked about the fact that New England's economy is not growing in population, but we have 70 percent of the people with disabilities ready to work if they could find a job. That statistic caused the press and the public to start to think: That is something they were not aware of in relationship to the geographical area. Once you get the attention of the press - they act. You have to have an angle because people submit articles all the time on different issues. When you have the topic and the angle, you've done the research on that issue. Thereafter you must make it very clear in the first or second paragraph what you are talking about.

Collect media contacts by looking in newspapers and publications to see who is writing articles around issues of disabilities. Keep track of those names, and when you think there's something that he or she should be aware of in disabilities, contact them. What gave me added value in my Op Ed is co-authoring it with someone well-known and/or respected in the news field. It added attention-getting credibility.

Be mindful that there are different audiences; and the stats to be used in your article are different for a local audience than for a statewide audience. There are also some very regional publications that you can write. Timing is critical. October is National Disability Employment Awareness month; so that's a month to consider. July is the anniversary of the signing of the ADA. September is a good time to talk and write about workforce issues. Summer months are good months to send any type of op eds because these are slow months.

Working relationships are important. If we start thinking of our neighbors and friends, who knows whom, that's how we develop relationships. Approach them on the idea of writing about the recommendations that are in the Report. Go to different people and say there are some really good things in this Report and have them highlight how important the Report is. What it takes is all of us being ambassadors and letting people know.

The Chair introduced the next speaker, Kimberly Romine, who has been Deputy Commissioner of the Administration for Native Americans, U.S. Department of Health and Human Services, since October 2004. She

has worked for the Bureau of Indian Affairs at the U.S. Department of Interior since the late 1970s.

Administration for Native Americans with Disabilities:

Kimberly Romine announced that Commissioner Stamps, Administration for Native Americans, had a conflict in her schedule that prevented her being here. She introduced PCPID members to the Administration for Native Americans and encouraged the Committee to partner with tribes and Native American organizations. ANA projects focus on strengthening community resources to promote independence, self-determination, and self-sufficiency, and our programs are flexible because Native American communities determine project needs.

Approximately 22 percent of Native American children have been diagnosed with intellectual disabilities, and within the State of Alaska, that percentage is even higher. Depending on the tribe and their location, our children largely suffer from fetal alcohol syndrome at a rate from two to 33 times higher than the national average. Native American parents feel they lack adequate information to benefit their children who suffer from these disabilities.

The ANA supports the President's goals to uphold the rights of people with intellectual disabilities to have businesses and to have health and employment opportunities that promote independence. The FY 2005 ANA program announcements are scheduled to be printed in the *Federal Register* on Thursday, February 3, and our program areas of interest encourage projects that support people with disabilities.

The Chair recognized the next speaker, Chris Curry, from Families Together for People with Disabilities. Ms. Curry has an extensive background in working with students with autism, multiple disabilities, and severe behavioral problems.

National Native American Families Together Program:

After a few remarks, Ms. Curry introduced Dr. Grayson Noley, Chair of the Governing Committee for the National Native American Families Together Parent Center.

Grayson Noley stated that he represents the National Native American Families Together Parent Center (NNAFT), the only nationally focused parent training

center, parent training information center, supported by the U.S. Department of Education Office of Special Education and Rehabilitation. The focus of NNAFT is to assure that American Indian children who have disabilities have access to the services to which they are entitled. NNAFT is a part of a grassroots parent advocacy network.

Ms. Curry introduced Dr. Susan Banks, who developed the program with her. She is on the faculty of Washington State University in special education. Her expertise is in Native American studies and assessment and early childhood.

Dr. Banks stated that the National Native Parent Training Center is one of a group of parent training centers, the only national one that is aimed at reaching out to tribes and helping the other parent training centers within the states and regions. Also, it links up and works with the tribes in their communities. We have many students with intellectual, medical, and mental health and physical health issues that aren't being addressed. Families need to be empowered to help with the decision making process, and also to link their children so that the children are empowered to do likewise as they transition to adulthood. We work on partnering and parent/professional partnerships because the schools historically have not been friendly for many of our families, and there is reluctance of some parents to use special education services.

Native American students score lower than any other racial and ethnic group in basic levels of reading, mathematics and history, according to *No Child Left Behind*. NNADT provides training on some of the specific needs that tribes identify. Native Americans count for about 1.3 percent of students with IEPs. Fetal Alcohol Syndrome is much higher for the Native American. Native American children are more than twice as likely to be diagnosed with intellectual challenges.

In some pockets, we have a higher representation of mental retardation depending on the level of poverty and other factors that influence whether a person is going to have fetal alcohol syndrome (FAS), fetal alcohol effect (FAE), and some other problems that cause intellectual disabilities. The data we get from the states is aggregated, so that we can't figure out what are the disability categories and where and how these children are being served or not served. We need to

develop a comprehensive data collection system.

At 5:35 p.m., the meeting was recessed to reconvene at 9:00 a.m. on Tuesday, February 1, 2005.

TUESDAY, FEBRUARY 01, 2005

The meeting reconvened at 9:05 a.m.

The Chair announced that the Committee was going to begin with a presentation on housing issues by Gene Stallings.

Mr. Gene Stallings stated that he was going to speak on long-term housing. He related that he has spoken to hundreds of parents that have just discovered that they had a child with Down syndrome. With the exception of a very few, the major concern, shortly after the baby was diagnosed, "what would happen to my baby when I die?" Over 83,000 people with an intellectual disability are on waiting lists.

Mr. Stallings raised the question, what are their options when we talk about where are they going to live? This Committee and the federal government would probably like to see individuals with intellectual disabilities own their own homes. With owning a home, comes responsibility.

Funding is a problem in planning for housing for people with intellectual disabilities. Mr. Stallings stated that he has suggested to homes, that they take out an insurance policy, make that home the beneficiary, then when they die, the child goes to that home with \$500,000 or \$1 million. If we could make that tax deductible, or have a program where people with a child that's disabled could take out a term insurance policy and some big company would contribute in this way, then eventually we could help fund facilities. Perhaps get the government to provide some pilot housing programs. Mr. Stallings would appreciate seeing the government build two per state, and see how they perform.

Mr. Stallings introduced Steve Allen, speaker on funding for affordable housing. Mr. Allen is a Senior Business Manager for the National Community Lending Center at Fannie Mae. He manages a single-family mortgage business that loans the money to the people that have disabilities.

Housing and Aging of Caregivers:

Mr. Steve Allen is in public policy work supporting life changes for people with disabilities. He stated that he works for a division in Fannie Mae that's focused on underserved markets. Fannie Mae identifies markets that lenders are not actively involved in because of the business opportunities that exist there. Fannie Mae offers the lender support to do this work and insurance to buy the loan. Look at the influence your Committee can have around public policy and making this issue a higher priority. The more we can develop policy and look to program development and both public and private funding to eliminate these barriers, there's going to be more opportunities. The issue of affordable, integrated, accessible, multifamily housing is the biggest crisis for people with disabilities. Fannie Mae tries to make informational material accessible to people with disabilities. Fannie Mae is also increasing lenders' awareness about this market.

Mr. Allen noted that people with disabilities don't like to identify that they have a disability. The census reflects that, but it's a terrific basis to work with. Mr. Allen works with lenders on discrimination around people with intellectual disabilities not being able to own a house. It's not only lenders; it's also title companies. A legal guardian is often used, both in establishing credit and as the mortgagor on the mortgage. Underwriting that supports people with disabilities is also being developed. There are very high income to expense ratios for people with disabilities. The more we can create employment opportunities for them, the more their income can increase, and the more housing opportunities they're going to have. Mr. Allen stated that the Committee may want to make recommendations around what needs to get done about creating more solutions that address housing issues.

Presenter Statements:

Mr. David Fleishman spoke on Housing Choice Voucher Home Ownership Program, formerly known as Section 8 in HUD. Under this program, we have established a home ownership program for the disabled where we actually step in and pay a portion of the actual mortgage payment. They've partnered, in some cases, with The National Home of Our Own Alliance. To get something like this initiated, contact your local housing authority and ask about the Housing Choice Voucher

Home Ownership Program. The website for finding the Voucher is <http://www.hud.gov/pih>.

The Chair stated that at our next meeting we will have a panel that will include Shelly Brantley, Director of Mental Retardation and Developmental Disabilities in Florida, to talk about the joint waiver project there and how the waiving of all prohibitions on the Medicaid side, as well as the Social Security income and assets limitation, the creation of the opportunity for an individual development account, the use of the PASS plan to allow people with disabilities to get access to postsecondary education and other good things that eventually will lead to work, will be here. Midland, Michigan and Madison, Wisconsin also have individual budgets for everyone. If we can get those individuals to come and talk to us, we will.

FOCUS AREA DISCUSSION - Emergency Preparedness

Ms. Kathy Hargett stated that she was not successful in getting an outside speaker, although she went after the top. The only experts on terrorism with regard to our population were people in New York City who were there for 9/11. They're interested but their schedule did not permit their attendance for today. They would like to come as a panel in the future.

The Department of Homeland Security asked us to be an advisor and participate in their Interagency Coordinating Council on Emergency Preparedness and Individuals with Disabilities. The Council was created last summer by Executive Order, with the goal to ensure that the federal government is addressing the unique needs of disabled people in emergency preparedness planning.

There is a national bio-terrorism hospital preparedness program, and they're first responders of the medical community with hospitals, clinics, or EMTs. When we think of terror we think of the 9/11 kinds of things, but that's not the only way that they can wreak havoc in this country. Many participants in the Council's meetings have disabilities... mobility issues, building access issues, but not people with developmental disabilities. We are not a monolith population. Our people range in understanding from very low to very high and many of our population have additional disabilities. Ms. Hargett noted the need to constantly remind them of this fact. Our population is underrepresented.

The focus group on **Emergency Preparedness** explored and categorized issues of concern for people living in the community, at home, on their own, as well as people in a school setting and a work setting. The group identified plans that need to be put in place to avoid problems. The categories include: disaster planning, medications, training, bioterrorism threat, people identification, and communication.

Group members also identified steps that are necessary after the emergency, including: provision of alternative transportation; documentation of where individuals who have been in lock down go when they're released; communication that is clear to people in a range of disabilities from very low functioning to very minimal disability; and a plan outlining how medication needs will be met (noting that there are Medicaid regulations that probably are a barrier).

Michael Rogers, a civilian member of the Committee and a self-advocate, and a consumer service professional employed in the state of Washington Developmental Disabilities Administration, talked about the Medicaid prescription issue. Mr. Rogers suggested that PCPID work to change certain Medicaid rules, including rules that say you can only buy medicines 30 days out, even though an advanced supply may be required in emergency situations; and you have a fire drill at work once a year. He believes drills should be mandatory more than once a year depending on what drill you're practicing.

Emergency preparedness should accommodate the needs of people with different levels of disabilities. Staff training should be provided on a consistent basis. Support staff for persons using electric wheelchairs must prepare for access to standard wheelchairs should power go out. Staff should also know how much medication is available, and if there are substitute medicines that may be taken.

Ms. Hargett expressed the need to establish regulations that mandate that there be training conducted and how often it should be conducted. People with intellectual disabilities should have information on their person that shows a set of emergency contacts, including a contact in another part of the country. She said the Focus Group on Emergency Preparedness wants to see it mandated that there be extensive drilling and practice in many different situations and settings. Training should extend beyond the disability community. It is

important to communicate to the people with developmental disabilities what their roles are in varied situations, and in the case of people with profound intellectual disabilities, it is important to communicate to the direct caregiver, case managers, and management staff.

Staff should be trained to recognize symptoms of a bio-terrorism threat. A triage should take place so that a medical professional, perhaps a nurse, would get a chance to look at this and identify the problem. Identification must be put on people who may not be capable of self identification. Cellular phones might be helpful for people who can handle them. The Department of Transportation is establishing a website to identify needs and provide guidance related to emergency preparedness for people with developmental disabilities.

The Department of Homeland Security is looking to us to get back to them with advice.

FOCUS AREA DISCUSSION - Direct Support Professional Challenges:

The next presenter was Amy Hewitt, a Research Associate and Director of Interdisciplinary Training at the University of Minnesota Institute on Community Integration, who spoke on direct support challenges.

Ms. Hewitt stated that the field has embraced a caretaking model of low-wages with unskilled workers taking care of our most vulnerable citizens. Research has connected the link between organizations that have high turnover, high vacancy rates, poor training programs, and the quality of life of the person to whom they're providing supports. General findings: 1) People with intellectual disabilities have poor healthcare outcomes, fewer opportunities for community inclusion, and a lot of family trauma for individuals who are still living in their family home; 2) Constant turnover in direct support staff causes feelings of fear, anxiety, and frustration in people with intellectual disabilities.

One in three supervisors leave their positions in the course of a calendar year because of low pay and limited or no benefits. High vacancy rates are filled by staff who are already burned out and working overtime. Caretaking is not recognized or valued as a profession.

In the last three decades where and how people with intellectual disabilities get services has changed tremendously. In all of the states more than half of people who receive services receive them in community settings in neighborhoods where typical people live. Many states have transitioned everybody, except people who have severe disabilities or have exhibited extreme behaviors, out of institutions.

The Chair noted that the 44,000 people in public institutions have intense needs and are found in nursing homes, too. Secretary Thompson introduced \$1.75 billion of Medicaid money that would give a bigger share of federal Medicaid to states interested in developing plans to move people in the community.

Ms. Hewitt stated that the National Alliance for Direct Support Professionals decided to re-build the Direct Support Profession. The job title is Direct Support Professional; the role is to assist individuals to live self-directive lives and to contribute to their communities and to encourage attitudes and behaviors that enhance inclusion in their community. Common elements of what constitutes a profession need to be incorporated.

The Department of Labor has identified skill and competency standards for up and coming industries that individuals need to have. The standards set out skills and competencies that direct support professionals need to have in order to do a good job. There are now Department of Labor apprenticeship standards and guidelines for the profession of direct support. It's the first attempt at trying to create a national curriculum that can be customized and used in a number of states. A number of states have purchased the license to provide this training to their direct support staff. It is currently being used by about 70,000 direct support professionals across the country. The NADSP also developed a code of ethics for direct support professionals which will be forwarded to you.

Ms. Hewitt asked the Committee, if it takes on the issue of direct support training, to consider the issue of supervisor training. There is a set of standards around the competencies supervisors need.

The Chair stated that the Administration on Developmental Disabilities could fund a project of national significance, several million dollars that go into big issues that relate to people exploring

research and demonstration. The Committee should talk with ADD about a project.

FULL COMMITTEE DISCUSSION OF FOCUS AREAS:

Kathy Hargett, the focus area leader on **emergency preparedness**, indicated that the current challenge is a matter of developing recommendations and feeding that information into the Interagency Council. She stated that if she had a cadre of people wanting to input to the topic, she would take responsibility for getting the information, and with our recommendations, passing it on to that Council.

The Chair noted that the issues being considered include excellent test cases for how you can get the information from the federal government to the people at the local level. The focus area leader responded that there is a need to contact the Developmental Disabilities Administrations in every state. The Citizen Corps is another organization that's already in existence under the Department of Homeland Security.

The Chair inquired if Homeland Security could fund development of a manual for persons with intellectual disabilities. The focus area leader replied that she will ask the Council.

James Brett, the focus group leader for **dental care**, related that the experts who were gathered have shown the existence of an unmet need for oral healthcare for people with intellectual disabilities. They came up with recommendations. He suggested that a report could be a one or two-page letter to the President or others. The Chair noted that they could help the Committee with the writing.

The focus area leader responded that Dr. Corbin introduced somebody yesterday from the Foundation that has just been hired, and may be a source for drafting information.

The Chair responded that the Committee should talk about how we would organize getting the work done if we were going to develop some short pieces on focus area issues. She suggested that each leader of a focus group work very closely with these speakers to understand that we want them to tell us what they know about the problem with respect to people with intellectual disabilities, and we want them to come

with solutions, best practices, or recommendations. The Chair noted the need for Committee members and staff to help shape the presentations that invited speakers present before the Committee. She said she would take on, by herself, somehow the issue of data; and that she would get Dr. Siperstein and other experts to help map out the topics and determine the data that we would want somebody in the federal government to be collecting.

The leader of the **emergency preparedness** group suggested that the Committee could address all five focus topics. We don't have to address all five topics in a fancy report. But it's incumbent on us, as the group leader for a particular topic, to get the information that we need and boil it down into a recommendations format.

A citizen member brought up the subject of different groupings among people with intellectual disabilities and suggested an alternative for a housing and employment approach. The Chair countered that statement. The recommendations around home ownership and control of resources, apply to all, including the ones in day programs and sheltered workshops. Our challenge is how do we get them out of that situation? They are not there by virtue of the fact that they have a significant disability. They are there because this is the set of systems that we have put in place that require them to be there.

Brenda Leath, leader for the focus group on **comprehensive health care**, stated that the Committee would want to make clear that we integrate these themes because we're trying to reduce the fragmented services that are provided to people with intellectual disabilities. Before the leader for the **direct care professionals** group left, she asked me to remind members that issues related to direct service professionals cuts across all of the areas. The Chair concurred that is true. When best practices are identified, we need to understand how they do the funding because often it's putting together pieces of funds from various funding streams in the absence of parents and individuals controlling the money. Regarding the focus areas, would you just say here are five topics, they're all important and we'll be publishing them in a series or is there some way to link them?

Ms. Leath stated that they are all linked. If you

don't talk about the connections, you're missing what we say is part of our mission to look at issues across a lifespan.

The leader for **emergency preparedness** indicated that they all don't need to be in a fancy report. The Chair responded that the Committee should try to link them.

A citizen member indicated that NADD is working with APA to add a supplement to the DSM-IV-R to evaluate people with developmental disabilities and intellectual disabilities. We need to work with the representatives of APA and NADD and AMA. The Chair replied that is something that the Committee can do. You can help us put together a couple of experts who can talk about mental health.

The Chair offered a suggestion that if the Committee had the work of research done and individuals who could help us with the writing, which the Committee would be reviewing periodically, the Committee might have one day of our meetings focus on the agenda and another day talk to people in the various agencies about these issues. She asked members what could be done to help them get to people at their state level that would make a difference and enable members to get to the stakeholders in their community. The objective would be to make them aware of the focus areas and problems related to them.

A focus group leader suggested that a letter of introduction from the Chair would be desirable to foster this approach.

The Chair noted that members can help shape the information and bring it to the PCPID meeting, so that we can have what we need for reviewing the subject as the speakers are presenting; outlining what we want and identifying the data we want included. The Chair noted the need for a writer for each topic who would take extensive notes and plan with us as we proceed.

The Executive Director stated that the Committee is operating right now under a Charter that states that we may have quarterly meetings if the money is available. She told Committee members that they may want to consider conference calls.

The Chair indicated an acceptance of the Charter limitations; and said the Committee may have conference calls. She raised the question, what do I

need to ask of you for the next meeting? Suggestions were offered by members. The Chair acknowledged two different proposals. One is that we would do a series of smaller reports that we could get out quickly; the other is to go through a process of exploring each topic, coming up with a statement of the problem, data, recommendations, and compile that into a single report in a year.

The Executive Director expressed concern about Homeland Security and the emergency preparedness focus area. Dr. Giannini has the lead authority at HHS and she's including information on people with disabilities in her HHS Report. The Executive Director asked, how are we to do a report on this topic when the Office on Disability is well into it? The Chair inquired as to the nature and scope of the population to be included in the HHS report. Would it include and focus on our population?

The leader of the focus group on **emergency preparedness** recognized the need to find out if it's more expedient to work through the Office on Disability. She noted that Dan Sutherland and Claudia Gordon, PCPID ex officio representatives from Homeland Security, are looking for us to be an advisor. The Chair indicated that we need extensive conversations with Dr. Giannini on this subject.

The Chair reminded members to identify a work group that they wanted to join and become part of by e-mail.

The Chair introduced the final speaker, Berthy DeLaRosa-Aponte, appointed to serve on the Ticket to Work and Work Incentive Advisory Panel by the White House in 2003. In October, 2004 Mrs. Aponte was designated by the President to chair the panel for a four-year term.

Ticket to Work and Work Incentives Advisory Panel: An Update:

Berthy De La Rosa-Aponte stated that the Ticket to Work Panel is part of the Ticket to Work and Work Incentive Act passed in 1999. It builds on the importance of economic freedom for people with disabilities. The Act is intended to motivate, promote, and facilitate employment of people with disabilities by protecting their health benefits. The Ticket to Work and Work Incentives Advisory Panel is bipartisan and comprised of 12 members who provide

counsel to the President, the Commissioner of Social Security, Congress, and other agencies on issues related to work incentive programs, planning, and assistance for individuals with disabilities and the Ticket to Work and Self-Sufficiency programs. It was established under Section 101 of the Ticket to Work and Work Incentives Improvement Act. Panel membership is diverse, including support providers, educators, a parent, and individuals with disabilities. Panel members serve on three committees: the Program, Design, Implementation, and Evaluation Committee; the Program on Legal Policy Committee; and the Planning and Operations Committee.

The Panel is governed by Public Law 92-463, as amended. It must abide by the FACA. Panel Meetings are published in the Federal Register, and are open to the public. The Panel has published annual reports since 2001. Panel members are working on their 2005 annual report and expecting completion in May. It's not going to be a detailed report, but more like a memorandum. The Panel has intermittent advice letters or reports on design issues relating to the adequacy of incentive studies, and the statutory requirements and design issues related to SSI 1 for 2 benefit offset research. Panel members commissioned different experts to provide briefing papers. They are moving from a lot of briefing papers that relate specifically to The Ticket to briefing papers that have to do with other areas like Medicaid buy-ins, Medicaid infrastructure grants, and labor.

Panel members not only advise on The Ticket, but also on other work incentives. Their charge includes other Social Security work incentives and Medicaid Medicare work incentives. Some things are going to need to be changed through the legislative process.

The Panel has responsibility for the planning for achieving self-sufficiency which helps people to accumulate above the \$2,000 asset limitation and still qualify for the SSI. Last year only 1,700 people in the United States had an approved PASS written. Under 1619(b) another work incentive called "Medicaid While Working," depending on the state in which they reside, people can make above the substantial gainful amount and still qualify for Medicaid services. Most people are not aware that they can use this work incentive and keep their benefits. The Panel is looking into asset development, the individual development accounts, and other ways for individuals to have assets and economic freedom. Panel members provide

congressional testimony and have regular meetings with Congress after which we meet quarterly; twice in Washington, D.C., and twice in other parts of the country, so they can hear comments from the general public, nationwide. Meetings are recorded and archived for public availability. The Panel is comprised of many standing committee meetings and teleconferences that are also conducted publicly. It wants to work with the Department of Labor and the HHS Office on Disability, so that we can send a common message.

Beginning in 1992, the Panel mailed The Ticket to everybody in the United States who is an SSI or SSDI beneficiary. With it, individuals can go to an employment network (a provider of services paid by Social Security on an outcome basis).

WRAP UP - Next Steps:

Summarizing, the Chair stated that the Committee has decided to pursue work in all five focus areas. Each focus area is equally important, although the timeframe may be different in terms of which gets emphasis at a particular time. The Committee will wait to make a decision about 1) whether it wants annual report with recommendations, 2) whether to do it in smaller bytes, or 3) whether to do a memorandum of advice similar to that as one of our guest speakers described.

A citizen member stated that she visited the Smithsonian American History Museum and saw a beautiful Brown v. Board of Education exhibit. She inquired, could we get the Smithsonian to do something with David Braddock's *Disability of the Dawn of the 21st Century*? They had an interactive set up with the Court decisions in a comprehensive way. Millions of people go through there to see exhibits. If they set up an asylum the way they were and had people walk through that experience, how powerful that may be. Perhaps that could be sponsored by Wal-Mart. The Chair responded that this was an interesting idea and something that the Committee should consider.

The Chair summarized the next steps for the Committee:

- 1) People will join a work group after they get the email that's going to come out.
- 2) The Committee will host conference calls with each work group to help them identify people/speakers, issues, and data.

3) The Committee will have a meeting around May 11.

The Chair noted that the Committee needs conference calls to decide what else would go in the document... perhaps some focus on a model, if there is one.

In health issues, there is adequate data. On housing, if HUD is willing to collaborate with us and pay expenses for an expert, we can do that using a Memorandum of Understanding. The Executive Director indicated that this may mean that The Committee will need to go over to HUD, make a presentation and try to sell them on the idea that we could collaborate. An ex officio member responded, you work on your own initiative and they put the money in. You can convince them that this is something that is part of what their authority is and that they should be doing it. You can always relate it to the "New Freedom Initiative".

The Executive Director stated that the Committee runs all of its memorandums of understanding through the Office on General Counsel. A citizen member inquired if the Committee had a copy of a Memorandum of Understanding (MOU) that he could look at? The Executive Director replied in the affirmative. An ex officio member indicated that the Committee may not need to go through the Office of General Counsel since the Office of Disability does not have to send an MOU through the OGC anymore. The Executive Director stated that she will check on this matter.

The Chair stated that the Committee needs the input of experts long before they get paid for their services; so Committee members have to identify people willing to work on that basis.

With no further business being considered, a motion to adjourn was entered, seconded and approved. The meeting was adjourned at 2:52 p.m. on Tuesday, February 01, 2005.

CATEGORICAL SUMMARY OF ACTION ITEMS

Education (Annette Talis):

1) Look on the IDEA Reauthorization website specifically identified in JoLeta Reynolds' presentation, and submit comments as appropriate. The following sections require the attention of PCPID:

"Highly qualified" [Section 602-10, which is the definitions section]

"Performance Goals and Indicators and Assessments" [Section 612(a)15 and 16]

"Access to Instructional Materials" [Section 612(a)23 and Section 612(a)6]

"Discipline Provisions" [Section 615(k)]

"Reducing Paperwork" [Section 609]

"IEP Team Attendance" [Section 614(d)]

"Multiyear IEP Demonstration Projects" [Section 614(d)]

"Early Intervening Services" [Section 613(f)]

"Model Forms" [Section 617]

"Infants, Toddlers, and Children" [Section 617(c)]

"Parents Choice" [Section 612(a)10]

"Medication Requirement" [Section 612(a)25]

"Parental Consent for Services" [Section 614(a)]
-- Parents have the right to determination if their child will receive special education services.

"Mediation" [Section 615(f)]

"Monitoring and What Matters Most" [Section 616]

"Research-Based Practices" [Section 614(b)]

2) Draft a letter transmitting PCPID recommendations on assessment in our existing Report, that we've already voted on, and forward those during the comment period for IDEA Reauthorization.

Assistive Technology (Claudia Coleman):

Send a letter to the National Institute for Disability and Rehabilitation Research about it's planned development of AT products (based on it's study of AT needs and AT usage amongst individuals with intellectual disabilities), outlining some of the things the PCPID is interested in being included.

Dental Care (James Brett):

Apply pressure to professional schools and request a meeting with the Head of the American Medical Association and ask, you're not teaching your students anything about treating people with intellectual disabilities? Dr. Perlman's "job would be to provide you with the information that you can take to them".

Housing (Gene Stallings):

Make recommendations around what needs to get done about creating more solutions that address housing issues. Gather information about the percent of people with disabilities that do own a home?

PCPID (Madeleine Will/Sally Atwater):

- 1) Invite a panel, including Shelly Brantley and others (folk from Midland, Michigan and Madison, Wisconsin) to talk about the joint waiver project and how the waiving of all prohibitions on the Medicaid side, as well as the Social Security income and assets limitation, the creation of the opportunity for an individual development account, the use of the PASS plan to allow people with disabilities to get access to postsecondary education and other good things that eventually will lead to work.
- 2) Talk with Pat Morrissey, Commissioner, The Administration on Developmental Disabilities, about funding a project of national significance, several million dollars, that go into big issues relating to people exploring research and demonstration in the area of Direct Support.
- 3) Take on the issue of data, and talk with Dr. Siperstein about helping to map out the topics and help identify the data we want somebody in federal government to be collecting.

Emergency Preparedness (Kathy Hargett):

- 1) Provide advice to the Department of Homeland Security regarding emergency preparedness for people with intellectual disabilities.
- 2) Respond to inquiry from Ken Lohff regarding the existence of an emergency preparedness plan for PCPID members during their Quarterly Meetings.
- 3) Inquire into the possibility of Homeland Security funding PCPID development of a manual addressing emergency preparedness for persons with intellectual disabilities.
- 4) Talk with Dr. Giannini to determine if it is more expedient to work with her (the Office on Disability) in responding to the request from Homeland Security for advice regarding emergency preparedness for people with intellectual disability. Ask if her office is going to issue a report that will focus, in part, on emergency preparedness for our population, or would they want us to extrapolate from a report that they prepared information about persons with intellectual disabilities? Ms. Hargett stated that she would need to find out if it's more expedient to work through Dr. Giannini.

ACTION ITEM (Presenter, Amy Hewitt):

Provide staff a copy of presentation handouts, and a copy of the Code of Ethics for Direct Support Professionals, for dissemination to Committee Members.

ACTION ITEM (Dr. Appareddy):

Help put together a couple of experts who can talk about mental health as PCPID embarks on plans to work with representatives of APA, NADD, and AMA to add a supplement to the DSM-IV-R to evaluate people with intellectual disability.

ACTION ITEM (Executive Director):

- 1) Send an e-mail asking Committee members to identify a focus work group that they wanted to join.
- 2) Check to see if all PCPID MoUs have to go through the Office of General Counsel.

- 3) Send a sample of a Memorandum of Understanding to Milton Aponte.

ACTION ITEMS - (PCPID Members):

- 1) Inform PCPID Executive Director of the focus group you would like to work with.
- 2) Look into getting the Smithsonian American History Museum do an exhibit (interactive asylum set up) exhibit with David Braddock's *Disability of the Dawn of the 21st Century*. Look into having Wal-Mart as sponsor.
- 3) Committee members will join a work group after they get the email that's going to come out. Conference calls will be arranged with each work group to help them identify people/speakers, issues, and data. A meeting will be held around May 11. Conference calls will be scheduled to decide what else would go in the document...maybe some focus on a model, if there is one.